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Family Conflict at the End-of-Life: An Examination of the Experiences of Hospice Primary Caregivers and Hospice Professionals

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Family Conflict at the End-of-Life: An Examination of the Experiences of Hospice Primary Caregivers and Hospice Professionals

by

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DEDICATION

This work is dedicated to all of the professional and family caregivers associated with hospice, particularly those who have experienced family conflict while continuing to provide compassionate, quality care to a dying individual.

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This dissertation represents the culmination of eight years of doctoral study. During this time I have given birth to, and begun to raise, two beautiful children with my husband Al. I have been a full-time faculty member and have attained tenure status at UW-Stevens Point. My work at UW-Stevens Point has given me the opportunity to teach and advise hundreds of undergraduates, work on other research projects, and contribute to the development of an emerging undergraduate social work program. When I set out to complete my doctorate, I promised myself that I would not allow it to take over my personal life or interfere with my job and that I would keep it in perspective. I feel that I have fulfilled that promise, though I would not have been able to do so without the support and assistance of my family, friends, colleagues, professors, and mentors.

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practical, and financial support throughout my years in higher education.

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subsequent work. I would like to specifically thank Dr. Don Mowry and Dr. Nick Smiar. Dr. Mowry provided me with my first opportunity to teach and to do research outside of class expectations through taking me on as a teaching and research assistant. This opportunity sparked an interest in academia and a beginning confidence in my teaching and research abilities. Dr. Smiar was the first to suggest that I might want to consider earning my Ph.D., which was something that I had not previously considered myself capable of. His suggestion that I apply for positions at UW-Eau Claire really meant a lot to me and provided a much needed confidence boost in pursuing this career path.

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Family Conflict at the End-of-Life: An Examination of the Experiences of Hospice Primary Caregivers and Hospice Professionals

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Guided by an explanatory matrix of family conflict at the end-of-life, the goals of this mixed methods study were to further generate theory regarding family conflict and to provide insights into its correlates and predictors. Sources of data analyzed include quantitative survey responses from 161 hospice family caregivers, 15 in-depth interviews with hospice family caregivers, and 10 interdisciplinary focus groups with hospice professionals. An explanatory matrix is presented that portrays family conflict at the end-of-life as a complex phenomenon influenced by salient contextual variables, conditions, and factors that may contribute to a number of negative outcomes for patients, family members, and professionals. The matrix also provides a beginning understanding

of approaches utilized by hospice professionals in their work with families experiencing conflict. Significant bivariate correlations were found between family conflict and family context variables (i.e. prior conflict, length of caregiving, caregiver gender, caregiver age, presence of children in the caregiver's home, advance planning discussions within family), conditions (i.e. family "coming out of the woodwork" and patient care needs) and contributing factors (i.e. communication constraints and family asserting control). In the multivariate model, significant predictors of family conflict included prior conflict, caregiver gender, caregiver age, advance planning discussions within family, family "coming out of the woodwork," communication constraints, and family asserting control; the model explained 60% of the variance in family conflict. Implications for routine assessment, further examination of interventions to prevent and address conflict, and future research are highlighted.

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CHAPTER 1—INTRODUCTION

The population of the United States is aging. Ongoing advances in medical technology, enhanced health resources, and improvements in the quality of health care available are contributing to longer lives. The "baby boomer" cohort will begin turning 65 in 2011, causing the anticipation of a significant swell in the older adult population in years to come. In 2003, those 65 years or older already numbered 35.9 million and represented 12.4 percent of the U.S. population (Administration on Aging, 2005). It is projected that by 2030 there will be about 71.5 million people in that age cohort, which will represent 20 percent of the population (Administration on Aging, 2005; Federal Interagency Forum on Aging-Related Statistics, 2006; Last Acts, 2001). The life expectancy for Americans is at an all-time high of 77.6 years (Centers for Disease Control, 2005), with length of life following retirement becoming greater as well (Federal Interagency Forum on Aging-Related Statistics, 2006). Those aged 85 and older represent the fastest growing segment of the nation's population, with numbers expected to reach 9.6 million by 2030 (Administration on Aging, 2005; Federal Interagency Forum on Aging-Related Statistics, 2006; Last Acts, 2001; World Health Organization, 1998).

A challenging consequence of this trend is the growing number of older adults living with and dying from chronic and terminal illnesses. Rather than being the sudden result of acute illness, infectious disease, or injury, death is now most likely to occur slowly, in old age, at the end of a period of chronic, progressive illness (Last Acts, 2001; Lorenz et al., 2004; National Alliance for Caregiving, 2003; National Institutes of Health,

2004; Stillion, 2003). According to the Centers for Disease Control (2005), 68.4 percent of deaths nationwide result from the top five chronic illnesses (heart disease, cancer, stroke, chronic obstructive pulmonary disease, and diabetes), and this figure is expected to increase to 75 percent by 2020. By the year 2030, nearly 150 million Americans will have some type of chronic illness, a 50 percent increase since 1995 (National Family Caregivers Association, 2005). For people 65 and older, chronic conditions (heart disease, cancer, cerebrovascular disease, respiratory disease, diabetes, and Alzheimer's disease) represent six of the seven leading causes of death (Federal Interagency Forum on Aging-Related Statistics, 2006). Hospice programs already served an estimated 1,060,000 patients in 2004, a 32 percent increase from 1994 (National Hospice and Palliative Care Organization, 2004). This number does not account for the many people with terminal illnesses who do not use hospice care.

The growth in the elder population is affecting many segments of society, challenging policymakers, families, businesses, social service organizations, and the health care industry to meet its needs (Federal Interagency Forum on Aging-Related Statistics, 2006). Older adults with chronic and terminal illnesses often have substantial physical, psychosocial, and practical care needs that may extend over weeks, months, or even years. Consumers and professionals are concerned about the adequacy of human and financial resources available to meet the needs of older adults in the near future. Older adults in America use more health care resources than any other age group, and health care costs are increasing (Federal Interagency Forum on Aging-Related Statistics,

2006; Jean-Baptiste & Lynn, 2004). The average annual health care costs for Medicare enrollees age 65 and older in 2003 was $12,510 and for those 85 and older it was $19,658 (Federal Interagency Forum on Aging-Related Statistics, 2006). Across the country, legislators are concerned that if left alone, today's long-term care system will "bust the bank"; already 35 percent of Medicaid's budget goes to long term care, most of it for care provided in institutions (Fox-Grage & Shaw, 2000). They view the situation of rising health care costs coupled with the aging of the nation with a certain level of crisis, projecting excessive costs, questioning the affordability of future care, and emphasizing cost containment as a solution (Keigher, 2000).

The current health care system does not reliably and effectively serve those living with chronic and terminal illnesses; it has not kept up with changes in life expectancy and evolving dying trajectories (Jean-Baptiste & Lynn, 2004). As a result, family members are increasingly assuming caregiving responsibilities (Emanuel et al., 1999; Grunfeld et al., 2004; Schulz et al., 2001). Already, family caregivers provide approximately 80 percent of all long-term services and supports for family members and friends across the lifespan (Emanuel et al., 1999; Haley et al., 2002; National Alliance for Caregiving, 2003; National Family Caregivers Association, 2005). As the primary caregiving institution in the United States, family caregivers are an estimated 44.4 million Americans, representing 21 percent of the U.S. adult population (Arno, Levine, & Memmott, 1999; National Alliance for Caregiving, 2003; U.S. Census Bureau, 2002). Nearly one in four households has a member providing care for an individual older than

50 who needs daily assistance (Family Caregiver Alliance, 2005).

Though most long-term care spending in the U.S. is for nursing home and other institutional care, the majority of elders live in the community with support from unpaid family members (Federal Interagency Forum on Aging-Related Statistics, 2006). For example, of the 10.7 percent of Medicare enrollees 65 and over who received personal care in 1999, 66 percent utilized only informal care, 26 percent used a combination of formal and informal care, and only 9 percent used formal care only (Federal Interagency Forum on Aging-Related Statistics, 2006). Among other factors, availability of caregivers has been identified as a significant determinant of care setting for frail elders following hospitalization, with elders who have more caregiver availability being more likely to return to less restrictive settings (Choi, 1999). The value of the services family caregivers provide for "free" is estimated to be $257 billion a year, twice as much as is spent on homecare and nursing home services, comparable to 20 percent of all health care spending (National Alliance for Caregiving, 2003; National Family Caregivers Association, 2005).

Though increasingly depended upon, family caregivers are more limited in availability than in years past (Hanson, Danis, & Garrett, 1997; Last Acts, 2001; Redding, 2000). Family members no longer live in close proximity to one another and families tend to be smaller due to higher rates of divorce and lower rates of marriage, remarriage, and birth (Byock, 2001; Last Acts, 2001; National Alliance for Caregiving, 2003). Though men and women of all ages assume caregiving roles, the typical caregiver

is a forty year old woman who provides more than twenty hours of care each week to her mother (Greene & Jones, 2007). Women now comprise almost half the labor force, however, leaving little time for caregiving responsibilities (Byock, 2001; Last Acts, 2001; National Alliance for Caregiving, 2003). By 2015 it is expected that 80 percent of women between the ages of 25 and 54, 60 percent of women ages 55 to 64, and 10 percent of those over 65 will be working outside of the home (Last Acts, 2001). As a result of these family trends and the changing roles of women in the workforce, family caregiving responsibilities will fall on relatively few shoulders for longer periods of time, with the chance of becoming a caregiver at some time in life being likely to increase in years to come (Marks, 1996; Rapp & Chao, 2000).

Changes in the dying trajectory have prompted changes in family roles at the end-of-life. With an increasing number of three and four generation families (Cutler, 1997) and greater variation in household and family composition and kinship arrangements (Moen & Forest, 1995), family caregiving has become more complex. As stated by Sherman (1998), "A person's family is often the primary source of physical and emotional support in times of distress…at no time is there greater stress than when a person is diagnosed with a terminal illness, which engenders myriad complex physical, emotional, social and spiritual needs" (p. 357). Caring for some who is dying is a family affair, and the entire family unit is affected when one of its members is terminally ill (Sherman, 1998). The need for family involvement is typically high, increasing as the illness progresses and possibly reaching a point of becoming an all encompassing

responsibility close to the patient's death (Haley et al., 2002; National Institutes of Health, 2004; Zuckerman & Wollner, 1999). More and more, families are assisting with pain and symptom management, care coordination, and household management (Lorenz et al., 2004). They are serving as advocates, brokers, liaisons, educators, supportive counselors, decision-makers and hands-on caregivers (Cochran, 1999). They are also assuming some financial responsibility for their dying relative's living and medical expenses, potentially compromising their own financial well-being. Because of their need to juggle caregiving, work, family, and their own health and mental health, caregivers need a different support system than what was available in past generations (Last Acts, 2001).

Family caregivers consistently report that they are not prepared for the intense demands associated with caregiving (National Alliance for Caregiving, 2003; Sherman, 1998). A number of trends may contribute to these feelings. First, a past trend towards institutionalizing dying individuals has left families ill-equipped to provide care in the home (Redding, 2000). As families have become more removed from the process of death, they have increasingly assumed that dying individuals receive better care in institutional settings than at home (O'Connor, 2003; Stillion, 2006). Second, the "medicalization of death" is contributing to a death-denying medical culture as professionals often view death as a failure of science to stop the death trajectory (Holloway & Quill, 2007; Redding, 2000). This medical culture leaves families with little opportunity to face and prepare for death, as an aggressive, cure-oriented philosophy

is often employed until close to death and palliative care is sometimes discouraged. Third, due to cost containment policies that limit hospital and nursing home use, patients with both acute and chronic conditions are transferred home with limited or no formal home care assistance (National Alliance for Caregiving, 2003; Redding, 2000; Sherman, 1998). Families are now expected to provide complex care that was once considered the realm of professionals (Ferrell, Virani, & Grant, 1998; Hudson, 2003a; Nezu, Palmatier, & Nezu, 2004; Sherman, 1998; Waldrop, 2006). Fourth, families involved in the U.S. healthcare system are often overwhelmed and confused by the volume of information and the pace at which it is delivered to them; they must cope with their loved one's impending death while responding to the requests being made of them by healthcare professionals (Jones, 2007). Deficiencies such as poor provider communication, inadequate pain and symptom management, insufficient training and emotional support for families, and fragmented care confound this challenge and lead to feelings of uncertainty, stress, and frustration (Byock, 2001; Greiner, Buhr, Phelps, & Ward, 2003; Hanson, Danis, & Garrett, 1997; SUPPORT Principal Investigators, 1995; Teno et al., 2004). Fifth, consumers are increasingly expected to be active participants in the dying process by making decisions, openly discussing concerns and needs, and expressing their grief (Blevins & Papadatou, 2006). As such, families must understand and comply with the culture of the U.S. healthcare system if they are to receive the care they want for themselves and their relative (Jones, 2007). Such approaches may be foreign to those who were socialized to respond stoically and passively, as was the case early in the

palliative care movement (Blevins & Papadatou, 2006).

Families respond differently to the stressors and demands associated with end-of-life care. How they respond, together with how their needs are met, influence the quality of care provided and caregiver well-being (Blasi, Hurley, & Volicer, 2002; Tilden, Tolle, Drach, & Perrin, 2004). Some families work together and move through the experience with relative ease, cooperating, supporting one another, and openly discussing feelings and thoughts. Others experience ongoing problems and disagreements, arguing about the practicalities of the situation, decisions that need to be made, and how to care for their relative. Hospice workers attest to these differences in family dynamics and assume the potential for conflict in each family they serve. In acknowledging the patient and their family as the "unit of care," they work to reduce caregiver burden, enhance family functioning, address family needs, and improve the quality of life of both patients and family members (National Consensus Project, 2004). Professionals have begun to give substantial attention to alleviating the difficulties of families who provide end-of-life care (Kinsella, Cooper, Picton, & Murtagh, 1998; Lynn et al., 1997). They realize that family needs, desires, and preferences must be understood and considered and that an important element of quality care involves supporting naturally occurring family caregiving networks (Americans for Better Care of the Dying, 2003; Early, Smith, Todd, & Bemm, 2000; Grbich, Maddocks, & Parker, 2001; Wennman-Larsen & Tishelman, 2002).

Researchers and other end-of-life experts also recognize that death and dying have a significant impact on family systems and their functioning. Leading experts

recently collaborated to establish clinical practice guidelines for quality palliative care, and family manifested as a significant element in each of their identified domains (National Consensus Project, 2004). Similarly, Last Acts (2001, 2002), in identifying key domains in end-of-life care, emphasized the need to treat the dying person in the context of his or her family. They noted that good end-of-life care includes a physical and emotional environment that is pleasant and supportive, time spent with loved ones, and care for dying persons and their families that respects their inherent dignity. Teno, Casey, Welch, & Edgman-Levitan (2001) developed a conceptual model of quality end-of-life care with input from patients, families, and experts as well as a structured review of professional guidelines. Among other elements, they claimed that quality care results when professionals promote shared decision-making and provide information and emotional support to family members.

End-of-life research agendas also call for increased attention to family experiences, difficulties, and well-being (Field & Cassel, 1997; Kramer, Christ, Bern-Klug, & Francoeur, 2005; National Hospice and Palliative Care Organization, 2004; National Institutes of Health, 2004) and numerous studies encourage more research related to both dying persons and their families (Byock, 2001; Casarett, Karlawish, & Byock, 2002; Last Acts, 2002; Reb, 2003; SUPPORT Principal Investigators, 1995). Research to date, however, has focused primarily on the terminally ill person and has not addressed the needs family caregivers and of the family as a whole (Waldrop, 2006). Additional research is much needed to address family caregiving and family dynamics at

the end-of-life. Though little attention has been given to these topics so far, federal funding priorities are likely to change as the elder population continues to grow and Medicare expenditures in the last year of life increase. The rise in end-of-life care expenditures is likely to pave the way for increased use of hospice and palliative care, intensifying the need for research in this area (Marks, 1998). With the current presidential administration's focus on health care reform, the issues associated with family caregiving at the end-of-life are likely to receive more attention.

Statement of the Problem

The U.S. population is aging, and more and more people are living with and dying from chronic and terminal illnesses. Because the U.S. health care system is not designed to provide the full range of care that dying individuals need, family members are often called upon to assume caregiving roles. Trends associated with family structure and roles at the end-of-life, as well as the extent to which family members feel prepared to care for a dying relative, contribute to a context ripe for family conflict. Families respond uniquely to the stressors associated with end-of-life, and how they respond significantly impacts patient well-being and family functioning. End-of-life advocates, professionals, and scholars recognize the importance of family, yet little research has explored the family dynamics associated with terminal illness and the interplay of factors that appear to impact family functioning. Family conflict at the end-of-life, though recognized by professionals as common, has not been given adequate attention in the literature. Further investigation of family conflict at the end-of-life is needed so that professionals and

policymakers are better able to meet the needs of families in a quality and cost-effective way. Without attention to their needs, the available pool of family caregivers may shrink as they suffer from physical, emotional, and financial problems that impede their ability to give care now and support their own care needs in the future (National Alliance for Caregiving, 2003).

Purpose of the Study, Hypotheses, and Research Questions

The overall aim of this study was to advance the knowledge base on family conflict at the end-of-life. As in Kramer, Boelk, & Auer (2009) and Kramer, Kavanaugh, Trentham-Dietz, Walsh, & Yonker (2009) family conflict was defined as "interpersonal tension or struggle among two or more persons whose opinions, values, needs, or expectations are opposing or incompatible." Guided by the explanatory matrix of family conflict at the end-of-life developed by Kramer et al. (2006) (Appendix 1), the goals were to further generate theory regarding family conflict at the end-of-life from the perspectives of hospice family caregivers and hospice professionals and to examine the relationships among family conflict at the end-of-life and other key variables. Previous research has suggested that in many instances provider and patient perspectives on physical and psychological needs are incongruent (Maquire, Walsh, Jeacock, & Kingston, 1999). Thus, gaining insight on this issue from both professionals and family members is an important contribution of this study. A concurrent triangulation mixed methods design was utilized in which survey, focus group, and interview data were collected.

Quantitative data were used to examine the correlates and predictors of family

conflict at the end-of-life. More specifically, this aspect of the study tested the following research hypotheses, which were generated from a review of the literature and the conceptual framework described by Kramer et al. (2006).

> **Hypothesis 1:** The family context will be associated with family conflict. More specifically, family conflict at the end-of-life will be higher among caregivers who report a prior history of conflict, absent or insufficient caregiving assistance from other family members, more family demands, fewer resources, and less advance care planning.
>
> **Hypothesis 2:** Certain conditions will be associated with the contributing factors to conflict and to family conflict itself. More specifically, caregivers who report the "coming out of the woodwork" phenomenon and greater patient care needs will experience higher levels of death anxiety, communication constraints, incongruent perceptions of care needs, and family conflict.
>
> **Hypothesis 3:** After controlling for the context and conditions, contributing factors (death anxiety, communication constraints, and family asserting control) will significantly predict family conflict.

Qualitative data were used to generate rich descriptions of the dynamics surrounding family conflict at the end-of-life. More specifically, the following research questions were addressed.

> **Research Question 1:** How do hospice primary caregivers experience family conflict while caring for their dying relative in terms of its context, conditions, contributing factors, and consequences?
>
> **Research Question 2:** How do hospice professionals view family conflict in terms of its context, conditions, contributing factors, and consequences?
>
> **Research Question 3:** From the perspectives of hospice primary caregivers and hospice professionals, what factors and/or interventions serve to prevent family conflict and/or mitigate the negative consequences associated with it?

CHAPTER 2—LITERATURE REVIEW

The following review of the literature encompasses a range of topics in an attempt to provide context for the current study. First, because the current study involves a focus on the experiences of family caregivers within their family systems, the literature regarding family caregiving is reviewed in terms of consequences, issues that contribute to caregiver stress, and factors that may mitigate stress for caregivers. Second, in direct relation to the study at hand, existing literature regarding family functioning is reviewed, followed by a discussion of research on family conflict, specifically. Third, because the notion of death anxiety as it relates to family conflict is examined in this study, a short segment discussing death anxiety and denial is included. Fourth, though the present study does not examine a particular intervention, a review of intervention research related to families is important, demonstrating little focus on interventions for families facing end-of-life and family conflict, specifically. Fifth, an overview of hospice is provided, focusing on services, philosophy, the role of social workers, and hospice in rural areas. The hospice context must be understood to make sense of the current study, and because the study site involves mainly rural areas, the unique challenges associated with rural hospice care should be acknowledged. Sixth, varying cultural perspectives on death and dying are presented. Though the present study does not examine differences related to diversity due to homogeneity of the study site, it is important to acknowledge that they may exist in the broader population. Seventh, and finally, theoretical perspectives are highlighted, with particular attention given to the main theoretical perspective underlying

the present study.

Family Caregiving at the End-of-Life

Consequences

Family caregiving and its consequences for caregivers of elders with chronic illnesses and/or disabilities have been studied widely over the last decade by a number of disciplines (Biegel, Sales, & Schulz, 1991; Coleman, Piles & Poggenpoel, 1994; Given & Given, 1991; Scharlach, 1994; Schulz & Beach, 1999; Schulz, Visintainer, & Williamson, 1990; Skaff & Pearlin, 1992; Smith, Smith, & Toseland, 1991; Teel & Press, 1999; Walker, Pratt, & Eddy, 1995). The majority of research concerning caregiving for people with chronic illnesses has focused on Alzheimer's disease and other forms of dementia (Chappell & Reid, 2002; Gaugler et al., 2004; Haley & Bailey, 1999; Haley et al., 1995; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Kiecolt-Glaser & Glaser, 2003; Ory, Yee, Tennstedt, & Schulz, 2000; Pinquart & Sorenson, 2003; Ponder, R. & Pomeroy, E., 1996; Rabins, Fitting, Eastham, & Zabora, 1990; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Schulz, Visintainer, & Williamson, 1990; Walker & Pomeroy, 1996). Increasing attention has been given, though, to caregiving in other stressful situations, such as caregiving for people with cancer (Blanchard, Albrecht, & Ruckdeschel, 1997; Ell, Nishimot, Mantell, & Hamovitch, 1998; Rabins et al., 1990; Weitzner, Haley, & Chen, 2000) and those who have experienced a stroke (Han & Haley, 1999). Overall these studies of caregiving have varied in methodology and have demonstrated mixed results regarding potential adverse and positive outcomes on

multiple domains of caregiver well being, mediators of burden, and caregiver needs and concerns.

The research base specifically addressing family caregiving at the end-of-life is just beginning to emerge, though the importance of this topic is clear. Studies suggest that family members are often the exclusive providers of assistance for older adults with chronic and terminal conditions (Emanuel et al., 1999; Haley, LaMonde, Han, Burton, & Schonwetter, 2003). Family members assuming the role of primary caregiver are typically spouses and adult children (Emanuel et al., 1999; Ferell, 1999). Many are women who do not live with their care recipient (Bull, 2001; Donelan et al., 2002). Studies have suggested that age, marital status, education, ethnicity, and employment are also predictors of becoming a caregiver, though studies have produced mixed results (Marks, 1996). Although primary care is typically provided by one individual, in many cases more than one family member is involved in the "caregiving network" in some way (Barer & Johnson, 1990).

While studies have attempted to identify risk factors associated with end-of-life caregiving, results of studies examining the relationship between specific caregiver characteristics and burden are somewhat mixed. One study of 44 primary caregivers of patients enrolled in hospice, for example, found that at risk caregivers were still working, had been providing care for a long time, and lived in a rural locale (Meyers & Gray, 2001). Overall, existing research suggests that each family caregiver responds in a unique way, with many reporting high levels of burden and adverse impacts on their mental,

emotional, physical, social, and financial well-being (Coleman, Piles, & Poggenpoel, 1994; Given et al., 2004; National Consensus Project, 2004; Tilden et al., 2004; Waldrop, Kramer, Skretny, Milch, & Finn, 2005). How family caregivers respond to, and are supported through, the intense experiences associated with caring for someone who is dying, can have a significant influence the dying person's quality of life and caregiver well-being (Waldrop et al., 2005).

Mentally and emotionally, studies demonstrate that end-of-life caregivers experience high levels of impairment and distress (Cameron, Franche, Cheung, & Stewart, 2002). Major symptoms identified include mood disturbance, anxiety, depression, and low life satisfaction (Axelsson & Sjoden, 1998; Emanuel et al., 2000; Haley, LaMonde, Han, Narramore, & Schonwetter., 2001; Hinton, 1994; Hodgson, Higginson, McDonnell, & Butters, 1997). Specifically, Emanuel et al., (2000) found that burden and depression were higher in family caregivers of patients with substantial care needs regardless of the specific terminal illness. Haley et al. (2001) found that hospice caregivers of patients with either lung cancer or dementia showed higher rates of depression, lower life satisfaction, and poorer self-rated health than non-caregiving controls. One study identified the quality of the relationship between the caregiver and the care recipient as a factor, with better relationship quality being directly related to lower levels of depression and decreased sense of role captivity for the caregiver (Lawrence, Tennstedt, & Assmann, 1998). Turner and colleagues (1997; 1994) found that male caregivers report higher levels of anxiety and depression compared with men who

are not caregivers, along with receiving less emotional support from others. In a longitudinal study involving 89 caregivers of women with advanced breast cancer, Grunfeld et al. (2004) found that caregivers experienced substantial anxiety and depression at the onset of the patient's illness with a significant increase in caregiver burden and depression when the patient reached a terminal stage of the illness.

A few studies suggest that caregiver physical well-being is adversely affected by the caregiving experience. One study, for example, demonstrated that family caregivers at the end-of-life are more likely to have poorer physical health than their non-caregiving counterparts (Haley et al., 2001). Another study suggested that caregivers for advanced cancer patients may even be at increased risk for cancer themselves (Cameron et al., 2002). Additional research has demonstrated that older spousal caregivers had a mortality risk that was 63% higher than noncaregiver controls, an increased number of physical symptoms, and a high burden of chronic illness and increased mortality when they became bereaved (Sales, Schulz, & Biegel, 1992; Schulz & Beach, 1999).

Another line of research has addressed the bereavement period following a caregiving experience (Aneshensel, Botticello, & Yamamoto-Mitani, 2004; Michael, Crowther, Schmid, & Allen, 2003; Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001; Schulz, Newsom, Fleissner, DeCamp, & Nieboer, 1997). According to Raphael (1983), as many as 1 in 3 bereavements result in a "morbid outcome or pathological patterns of grief," equating to 5-6 million new cases of familial complicated mourning each year (p. 64). Relevant to the issues explored in this study,

Rando (1993) suggests that a pre-death relationship with the deceased that was markedly angry, ambivalent, or dependent; mental health problems; and the mourner's perceived lack of social support may increase the risk for complicated mourning. Rando (1993) further cites the breakdown of the nuclear family, increases in single parent and blended families, less contact among extended family members, and weakened links among family members as a result of the exclusion of the aged in our society, as trends affecting grief and mourning. Increased lifespan, altered mortality rates, lengthier chronic illnesses, intensified bioethical dilemmas, and a culture of closed communication about death have also had an impact on the way that families approach an end-of-life situation and the resources they have available. Family caregivers can feel very vulnerable after a relative's death, often having focused intensely on care provision for a lengthy period of time. Studies have suggested that caregivers are at an increased risk for depression, tobacco and alcohol consumption, sleep disruption, and mortality during the bereavement period (Penson, Green, Chabner, & Lynch, 2002; Bedell, Cadenhead, & Graboys, 2001). Factors identified as promoting bereavement adjustment include caregiver support during the dying individual's illness (Bass, Bowman, & Noelker, 1991), the provision of palliative care to patients and bereavement services to family caregivers (Cameron & Parkes, 1983), high quality communication and information offered to family while their relative is still living (Main, 2000), and lower levels of strain and care provision during the dying process (Schultz et al., 2001; Schulz et al., 2003).

As indicated, most caregiving research to date has focused on negative outcomes.

This lack of attention to the positive aspects skews our perceptions of the caregiving experience, limits the potential for strengths-based interventions, and introduces bias in research (Kramer, 1997; Riley, in press; Walker, Pratt, & Eddy, 1995). Because of this deficiency, a surge of interest in the study of "caregiver gain" has occurred over the past decade (Kramer, 1997). Kramer (1997) conducted a thorough search and review of such studies, mainly finding studies of caregivers for those with dementia and Alzheimer's disease as well as other chronic conditions, functional limitations, and mental illness. The studies suggest the potential for positive outcomes associated with caregiving such as satisfaction, pleasure, reward, enjoyment, growth, and meaning. Caregiver gain at the end-of-life has received even less attention in the literature. While it is possible that some of the care receivers in Kramer's (1997) review were dying, none of the studies included samples of end-of-life caregivers, specifically. Few studies conducted since Kramer's (1997) review addressed the experiences of end-of-life caregivers. Salmon, Kwak, Acquaviva, Egan, & Brandt (2005) cited the potential for personal growth, opportunity, and transformation that end-of-life caregiving brings, but based their ideas on anecdotal evidence provided by hospice workers. In Haley et al.'s (2001) study of spousal family caregivers of hospice patients with dementia and lung cancer, many reported experiencing a sense of satisfaction and feelings of closeness to their relative. They reported the benefits of modeling caregiving for their children, giving something back to someone who had cared for them, gaining satisfaction from knowing their relative was getting good care, feeling a sense of personal growth, and gaining meaning and purpose

in life. Waldrop et al. (2005) reported the additional positive consequences associated with end-of-life caregiving of heightened development and meaning making.

Contributing Factors

Studies relate adverse reactions to the stressors associated with end-of-life caregiving. Identified stressors and challenges include having strangers in the home (Sherman, 1998), insufficient time for self (Hull, 1990; Wennman-Larsen & Tishelman, 2002), having to make physical adaptations to the home (Sherman, 1998), balancing work with other responsibilities (Sherman, 1998; Waldrop et al., 2005), financial strain (Covinsky et al., 1994; Emanuel et al., 2000; Grunfeld et al, 2004; Schulz et al., 2003; Waldrop et al., 2005; Wennman-Larsen & Tishelman, 2002), social isolation and relationship fluctuations (Cameron, 2002; Farber et al., 2003; Hull, 1990; Sherman, 1998; Wennman-Larsen & Tishelman, 2002), feelings of powerlessness and fear about the disease process (Sherman, 1998), patient symptom and personal care needs (Axelsson & Sjoden, 1998; Emanuel et al., 2000; Farber et al., 2003; Hull, 1990; Kelly et al., 1999; Schumacher, Dodd, & Paul, 1993; Sherman, 1998; Wennman-Larsen & Tishelman, 2002), having to learn new skills (Wennman-Larsen & Tishelman, 2002), changes in patient mental status and patient psychological distress (Hull, 1990; Redingbaugh, Baum, Tarbell, & Arnold, 2003), declines in patient quality of life (Axelsson & Sjoden, 1998; Emanuel et al., 2000; Kelly et al., 1999; Redingbaugh et al., 2003; Schumacher, Dodd, & Paul, 1993), conflicting feelings (Hull, 1990; Sherman, 1998), changes in family identity, roles, responsibilities, and functioning (Hull, 1990; Sherman, 1998; Waldrop et al.,

2005), dealing with well-meaning friends and family members (Hull, 1990), and attending to one's own personal and situational needs (Farber et al., 2003). Further, caregivers who do not perceive that caregiving is a choice may be at greater risk for stress not only during but also after the caregiving period (Wennman-Larsen & Tishelman, 2002). In some instances the negative aspects associated with caregiving may become significant enough that caregivers experience emotional exhaustion and can no long provide care to the patient who then needs to seek alternative care, typically in an institutional setting (Haley et al., 2001; Lindgren, 1990).

Transitions have been identified in the literature as particularly stressful for caregivers. Chick & Meleis (2000) define transitions as passages from one life phase, condition, or status to another, noting that they are both the process and outcome of complex person-environment interactions that are embedded in the context and situation. Transitions signify a time of disruption and disconnectedness bounded by relatively stable periods of time (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). They require the caregiver to incorporate new knowledge, change behavior, and change the definition of self in social context (Meleis, 1997). Davies, Reimer, & Marten (1994), write that family members are in transition from living with the disease to anticipating the death of their loved one from the disease. The transition begins when family members make significant attempts to redefine their life situations, often radically, in terms of how they view themselves, the patient, and each other (Davies, Reimer, & Marten, 1995; Wennman-Larsen & Tishelman, 2002). Family members must live day to day, while also

preparing for death on practical, cognitive, and emotional levels (Davies, Reimer, & Marten, 1995). Coping with changes involves taking on additional responsibilities, offering support to others as they cope with the emotional aspects of role change, attaining or maintaining meaningful relationships, affirming spiritual values, changing life priorities, and examining how the experience of illness has contributed to personal growth (Davies, Reimer, & Marten, 1995).

According to Aneshensel & colleagues (1995), transitions occur from one stage of caregiving to another and transitional events may occur within each stage. Pearlin (1992) conceptualizes end-of-life caregiving as involving three stages, with each including challenges that contribute to caregiver strain. The first stage, role acquisition, is a process precipitated by onset of the illness and the care recipient's needs. The second stage, role enactment, involves performance of role-related tasks within the home or in an institutional setting. The third stage, role disengagement, is the period following death and involving bereavement and recovery. Stressors are influenced by transitional events that move caregivers from one stage to another including illness onset, nursing home admission, comprehension of terminality, and patient death (Hauser and Kramer, 2004). At each stage and at the time of these transitional experiences, caregiver roles, tasks and needs may differ.

The transition to end-stage caregiving can be particularly difficult for family caregivers. Based on interviews with recently bereaved adult family caregivers of cancer patients, Yates & Stetz (1999) generated five major themes related to how family

caregivers respond to an awareness that their relative is dying. They identified, "being uncertain" and "agonizing" as emotional struggles that families face as they grapple with observations and evidence that the disease is progressing and "hoping," "pretending" and "preparing" as strategies used by family caregivers to manage these emotional struggles. Kramer et al. (2006) also found that the period surrounding "death awareness" has a significant impact on family and caregiver functioning. In their model of family conflict at the end-of-life, "death awareness" is depicted as an antecedent influencing family conflict and its consequences. In trying to understand how caregivers make the transition to end-stage caregiving, Waldrop et al. (2005) identified the theme "comprehension of terminality," as significant to caregiver well-being. "Comprehension of terminality" describes a new state of awareness that death will be the inevitable outcome of the illness. It occurs as a result of receiving and assimilating concrete information about the illness, observing physical decline, and observing personality change and role loss. In a study examining the perceptions of patients, caregivers, and physicians, participants identified "awareness of impending death" as a primary challenge related to their experience with end-of-life care (Farber et al., 2003). This process involves interpreting and embracing the impact of terminal illness on the life experience and is associated with uncertainty, unpredictability, and the impending end of a relationship with the patient.

Making decisions with and on behalf of a family member has been identified as another significant challenge faced by family caregivers at the end-of-life (Caron, Griffith, & Arcand, 2005; Meeker, 2004; Meeker & Jezewski, 2004; Waldrop et al.,

2005). Advance directives have become legally recognized documents in all states, with the power of attorney for health care and living will being the most common forms. The power of attorney for health care is the more comprehensive document, authorizing a person designated by the patient to make medical decisions for the patient, in the event of the patient's incapacity or inability to make decisions. Though forms vary from state to state, most also allow the patient's representative to authorize the withdrawal or withholding of life support and placement in nursing homes or group homes for other than short-term stays. Despite the requirement of the Patient Self-Determination Act (PSDA) of 1991 that health care providers tell patients about advance directives, few Americans actually complete such documents (Last Acts, 2002). One study estimated the overall prevalence of advance directives in the general population to be 15 to 20 percent (Schwartz et al., 2002).

Dying individuals and their families are faced with difficult decisions regarding issues such as life-sustaining measures, treatments, location of death, care provision, and finances. Enhanced medical technology and the emphasis on "treating at all costs" have created a growing emphasis on patient rights, advance directives, and self-determination. Associated legal standards emphasize individual decision-making and the value of autonomy, yet most dying individuals do not make decisions alone. End-of-life decision-making and advance planning certainly takes place within a family context (Allen & Shuster, 2002). The roles of family members are frequently more complex and intertwined with the patient's interests than the autonomy decision framework allows

(Haley et al., 2002; Levine & Zuckerman, 1999).

Completing a power of attorney for health care may help with decision-making, but difficulties and uncertainties may still occur. Legally appointed proxies may make decisions that create distress or disagreement among family members (Doukas & Hardwig, 2003), are not in accordance with the patient's actual wishes (Allen & Shuster, 2002; Coppola & Ditto, 2001; Ditto et al., 2001; Field & Cassel, 1997; Miles & Koepp, 1996), do not accurately reflect patient needs (Allen, Haley, Small, & McMillan, 2002; Miaskowski, Zimmer, Barrett, Dibble, & Wallhagen, 1997) and/or are not supported by medical personnel. The role of decisional proxy has been cited as a particularly stressful one for family caregivers (Allen & Shuster, 2002). Family caregivers may be stressed by the need to balance their own needs and wishes with those of their family member. They may also feel uncertain as to what their loved one would want. Differences in perceptions and preferences might lead to conflict, uncertainty, and problems with treatment and care provision.

Another challenge identified by researchers is that of dealing with the medical system and other formal and informal service providers. Dying individuals typically have complex medical conditions and functional limitations, requiring services from many parts of the medical and long-term care systems. As end-of-life care is moving out of hospitals and families are replacing professionals in the delivery of care, the linkage between informal and formal caregiving is paramount (Waldrop, 2006). Unfortunately, coordination of information and services within and between these systems rarely occurs

(National Alliance for Caregiving, 2003). In 2000, 50 percent of caregivers reported that different providers gave different diagnoses for the same set of symptoms and 62 percent reported that different providers gave other conflicting information (National Alliance for Caregiving, 2003). Studies have demonstrated that family caregivers have a difficult time getting adequate information and attention from physicians (Hockley, Dunlop, & Davies, 1989; Slutsman, Emanuel, Fairclough, Bottorff, & Emanuel, 2002). Another study involving the perspectives of professionals employed by a fully integrated managed care program for older adults found that support systems demonstrate minimal skill in providing quality end-of-life care (Kramer & Auer, 2005). Formal and informal resources or supports were not available and/or were not willing to partner with the professional team. In their mortality follow-back survey of family members or other knowledgeable informants representing 1578 decedents, Teno et al. (2004) found that bereaved family members report high rates of unmet needs for symptom management, concerns with physician communication about medical decision making, a lack of emotional support for themselves, and a belief that their dying loved one was not always treated with respect. Caregivers must compensate for shortcomings in the medical system by becoming care coordinators themselves, ensuring that treatments prescribed by different providers do not conflict and ensuring that important medical and functional information travels across providers, settings, and over time (National Alliance for Caregiving, 2003).

Related to this challenge, hospice and palliative care programs are underutilized.

Less than one third of dying individuals overall use hospice (Friedman, Harwood, & Schields, 2002), and only one in five eligible under the Medicare Hospice Benefit receive hospice care (Brickner, Scannell, Marquet, & Ackerson, 2004). Hospice referrals are often made very late in the disease process or not at all. The average length of service in 2005 was 59 days, with the median length of service (which is a more accurate gauge in understanding the experiences of the typical hospice patient) being 26 days (National Hospice and Palliative Care Organization, 2006). A substantial number of hospice patients die within 7 days of entering the program (National Hospice and Palliative Care Organization, 2006). Accordingly, some describe hospice as "brink-of-death care" rather than end-of-life care (Last Acts, 2001). Since short lengths of stay require resource intensive interventions, dying individuals and their families often do not have the full range of care options that may be available earlier in the disease process (Christakis & Escarce, 1996).

Barriers limiting hospice utilization include 1) the prognostic uncertainty of many diseases, especially non-cancer conditions (Brickner et al., 2004; Last Acts, 2001; Lorenz et al., 2004; Martin, 2005; Reb, 2003) which all-together accounted for only 54 percent of all hospice admissions in 2004 (National Hospice and Palliative Care Organization, 2004), 2) access challenges for non-white individuals (Corless & Nicholas, 2003) who comprised only 22 percent of all hospice patients in 2004 (National Hospice and Palliative Care Organization, 2004), 3) admission restrictions for those receiving complex palliative treatments (Lorenz et al., 2004), 4) aggressive oversight by Medicare fiscal

intermediaries that has caused physicians and hospice programs to be overly cautious with admitting patients due to fearing allegations of fraud and abuse (Last Acts, 2001; Martin, 2005), 5) lack of access in rural areas (Corless & Nicholas, 2003), and 6) patients, families, and physicians having difficulty discussing and accepting death, lacking awareness or understanding of hospice, and/or being unwilling to move from curative to comfort care (Friedman, Harwood, & Shields, 2002; Martin, 2005). Additional palliative care programs are available through hospitals, nursing homes, and home health agencies, reducing the impact of these barriers, though these programs are also underutilized and not widely recognized by reimbursement sources.

Mediating and Moderating Factors

A number of coping strategies have been identified that may mediate caregiver burden and enhance well-being for caregivers involved in end-of-life care. In an examination of the experiences of older female caregivers in home hospice, Phimister (1991) concluded that deficiencies in external supports were often offset by the commitment of the caregivers and that successful caregiver coping was associated with a strong self-concept and an ability to place the caregiving in a meaningful context. In a study involving 31 family caregivers and their terminally ill relatives, Redinbaugh et al. (2003) found that lower levels of caregiver strain were associated with caregivers who stated that their families accepted the patient's illness. They also concluded that lower levels of strain were associated with caregivers who said that their families defined illness-related problems in a manageable way and felt capable of solving problems

associated with end-of-life care. Additional studies suggest that caregivers who use more problem-focused coping and who think their coping is effective report less strain than caregivers who report lower coping efficacy and use fewer problem-solving strategies (Kelly et al., 1999; Schumacher, Dodd, & Paul, 1993). In a phenomenological study of hospice family caregivers, participants identified the coping strategies of utilizing sources of support; engaging in adaptive activities such as laughter, reasoning, and establishing a routine; relying on spiritual beliefs, and avoidance behaviors as aids to stress reduction (Brinson & Brunk, 2000).

In a qualitative study of 88 African American family caregivers, "working out systems" was identified by participants as the main strategy that made caregiving more manageable (Turner, Wallace, Anderson, & Bird, 2004). "Working out systems" was defined as the process used by caregivers to share caregiving responsibilities among family members. This process was important with respect to responding to a specific care receiver problem, coordinating caregiver activities, balancing caregiving and other life demands, working with the health care delivery system, and planning for anticipated changes in caregiving patterns. Participants in this study also cited the importance of faith, family communication, support groups, and trust in the system (Turner et al., 2004).

Related to this, studies have found that adequacy of social support acts as a buffer between stressful life events and adverse physical and psychological symptoms and may also have a direct positive impact on physical and psychological well-being (see Choi & Wodarski, 1996 and Zimet, Dahlem, Zimet, & Farley, 1988 for useful reviews). Higher

levels of social participation, larger social networks, and higher perceptions of the adequacy of social support have been found to reduce the risk of depression and increase life satisfaction in hospice caregivers (Brinson, 2000; Haley et al., 2003; Hull, 1997). In a study conducted by Goldstein et al. (2004), the highest levels of caregiver burden were reported by caregivers with more limited social networks. Hull's (1993) research supports this finding, indicating that social support relates to reduced burnout in that it helps hospice caregivers deal with the overall caregiving responsibility, the uncertainty of the situation, and changes in the patient's mental status. Caregivers in this study identified the hospice nurse as a primary source of support, with other sources including family, friends, and neighbors. Other studies also cite the importance of hospice professionals as sources of support (Newton, Bell, Lambert, & Fearing, 2002; Kirschling, Stewart, & Archbold, 1994).

Family Functioning and Terminal Illness

It is a basic societal assumption that families have a responsibility to provide for the basic physical and health needs of its members (Leonard, Enzle, MacTavish, Cumming, & Cumming, 1995). Dying individuals face their approaching deaths within their own naturally occurring and distinct family and social networks, with end-of-life caregiving being the culmination of lifelong relationships and enduring family care (Waldrop, 2006). End-of-life care takes place within the context of family relationships, and families bring their existing dynamics with them into the end-of-life situation (Kristjanson, 1997; Waldrop, 2006). Cohesive families may become more closely

bonded and more cohesive, pulling together to support one another and their dying family member. Conversely, normally cohesive families may start to have disputes regarding care issues, falter in providing support to one another, and distance themselves from one another and their dying member. Families with preexisting difficulties may set them aside to focus on care provision, and may find the terminal condition an impetus for the resolution of family discord. On the other hand, preexisting conflicts may be exacerbated by the stressful situation, and families may not be able to work together to provide quality end-of-life care.

In one line of research, Kissane & colleagues (Kissane et al., 1994) used cluster analysis to define a typology of how adult families caring for a dying parent functioned. Five types of families emerged, including two that were viewed as well-functioning ("supportive" and "conflict resolvers,") two that were considered dysfunctional ("hostile" and "sullen" families,) and one type termed "intermediate." Level of functioning was found to be predictive of psychosocial outcomes such as depression, distress, and grief, during the palliative care and bereavement period (Kissane et al., 1994a; Kissane et al., 1994b). Deeply ingrained patterns of interacting and relating are difficult to change during times of challenge. Coping and communication styles are often passed down transgenerationally within families (Kissane et al, 1994; Weihs & Reiss, 2000). Openness about death and dying issues varies from family to family, with many families not openly talking about such issues. In a recent survey of over 3000 Idaho residents, for example, less than 50% remembered death and dying being talked about either

occasionally or often in their families when they were children (Simpson-Whitaker, Totten, & Moffat-Miller, 2006).

Terminal illness changes the family system, with coping strategies and previously agreed upon roles being challenged (Jones, 2007). The ability of a family to manage the stressors associated with terminal illness is influenced by past and present dynamics as well as contextual and situational factors that may or may not be associated with the terminal situation. Situational factors include feelings of losing control (Redding, 2000), role shifts that take place within families, and the need to balance caregiving and family life with other responsibilities. In their research involving professional perspectives of the challenges associated with providing quality end-of-life care, Kramer & Auer (2005) suggested that family resources may be stressed due to financial hardships and external demands, enduring and situational family conflicts, competing needs of family members, and the precarious psychological well being of family members. Other life issues associated with employment, caregiving for other family members, attending to small children and/or adolescents, and dealing with financial struggles do not disappear when a family member becomes terminally ill, and families often struggle to maintain their functioning while meeting their loved one's increasing physical and emotional needs (Jones, 2007; Sherman, 1998).

Glaser's & Strauss' (1965/1968) conceptualizations of *awareness context* and *dying trajectory* provide further insight on varying family responses at the end-of-life. *Awareness context* refers to who, in the dying situation, knows what about the

probabilities of death for the dying patient. Glaser & Strauss (1965) claim that who knows what makes a significant difference in family reactions. Within a single family, members may be at different stages of grieving because each member may have a different kind of death expectation, may be brought into awareness at a different time, and/or may require more or less time for grieving. Yates & Stetz (1999) note that family members' awareness contexts determine the way they will respond, adjust, and prepare for death. The extent to which involved parties are open versus closed greatly influences the extent of awareness and responses to the dying process. Glaser & Strauss (1965) further discuss how family members who are outside of an open awareness context are typically brought into awareness as soon as they arrive on the scene. A *dying trajectory* refers to the length, course, shape, and pattern of the final portion of a dying person's life, as well as the work it requires for both the dying person and those caring for that person (Glaser & Strauss, 1968). Different types of trajectories create different kinds of work for those involved. Needs, concerns, difficulties, and stresses are closely related to the course and treatment of a given illness, with the perspectives of family changing over time due to their own situations and their relatives' changing condition (Hull, 1990).

Most studies involving family issues at the end-of-life have examined the experiences of just one family member, typically the primary caregiver. While studies of caregivers enhance our understanding of the experiences and needs of family members, they do not allow for an examination of family functioning as a whole. Some research has been done, though, related to various family issues and dynamics at the end-of-life.

Smith (1990) found that the way in which a family manages the threat of a loved one's death depends on how well it has coped with adjustments that it has already had to make during the family's life cycle. Families develop communication patterns and roles to deal with challenges throughout everyday life that may influence coping during a time of crisis. Levitt (1986) identified six factors that enable a family to function when faced with a member's terminal illness: 1) the ability to work as a cohesive unit, 2) prior successful experience of handling stress, 3) the existence of a large and flexible coping repertoire, 4) the absence of a major period of instability resulting from family developmental issues, 5) the availability of outside support that the family wants, and 6) a willingness on the part of the family to perceive a difficult period as potentially growth producing. Waldrop's (2006) qualitative research involving 64 family members stressed the importance of a family network's ability to develop relationships with others in the social network to provide end-of-life care. In a study of patients referred to a palliative care home-care service, Tiernan et al. (2002) found that along with inadequate community resources and uncontrolled symptoms, the inability of the family to cope was a main reason for inability to keep the patient in the home. Hudson, Aranda, & Kristjanson (2004) identified multiple family-related issues that serve as barriers to effective palliative care, including challenges related to family functioning, lack of congruence between patient needs and family needs, "conspiracies of silence" about what topics or issues the family and patient discuss and acknowledge, and reluctance of families to bring up needs as to not bother the health care provider.

According to Levine & Zuckerman (1999), the literature and the practice of medicine reflect "a persistent tendency to equate families with trouble" (p.148). A number of factors contribute to negative presumptions about families including western medicine's focus on individualism, differing perceptions of family roles and functions, family conflict, challenges to professional authority, fear of litigation, and differing religious, ethnic, and cultural traditions (Levine & Zuckerman, 1999). Families are often labeled "dysfunctional" when they do not conform to expected behaviors, though family behavior may be a direct result of difficulty coping with the extreme stress of terminal illness (Levine & Zuckerman, 1999). Few families are perfectly cohesive, and under stress of illness, hidden tensions can erupt. In a study in which hospital counsel and medical staff were asked what created the most difficult situations in end-of-life care, nearly all respondents declared "families" (Zuckerman, 1999). Levine & Zuckerman (1999) feel that professionals have a hard time acknowledging the impact that terminal illness can have on the family, becoming frustrated when families "interfere" or are "difficult" to work with.

Family Conflict at the End-of-Life

Conflict has emerged as an important variable in studies of caregiving in later life families. It has been examined mainly with respect to caregiving for frail elders (Strawbridge & Wallhagen, 1991), people who have had a stroke (Anderson, Linto, & Stewart-Wynne, 1995; Bishop & Evans, 1995), and people with dementia (Davis, 1997; Fisher & Lieberman, 1996; Gaugler, Pearlin, Leitsch, & Davey, 2001; Lieberman &

Fisher, 1999; Neufeld & Harrison, 2003; Semple, 1992). Causes of family conflict identified in this line of research include the perception of one family member that another is providing insufficient help (Strawbridge & Wallhagen, 1991), lack of agreement regarding care coordination, patient needs, and the nature of the illness, (Davis, 1997; Neufeld & Harrison, 2003) and spillover from longstanding issues in the family (Neufeld & Harrison, 2003). Consequences consist of caregiver burden and poor personal health (Schofield, 1998; Strawbridge & Wallhagen, 1991), barriers to nursing home placement (Gaugler et al., 2001), caregiver depression and anger (Semple, 1992), and difficult bereavement (Kissane et al., 1996). Buffers identified include the use of a focused decision-making style and positive conflict resolution methods (Lieberman & Fisher, 1999). Avoidance of conflict has been linked with reductions in caregiver health and well-being as well as vulnerability to distress from increasing patient care over time (Fisher & Lieberman, 1996).

Family conflict has been defined in a number of ways in the aging and health care literature. Davis (1997) defines it as recurrent, stressful differences and disagreements between two or more family members around caregiving activities. Gaugler & Zarit (1999) define it as tension, interpersonal struggles, or outright hostility among caregivers and other family members outside of the caregiver-care recipient dyad. Strawbridge & Wallhagen (1991) suggest that family conflict is a clash or strong feeling of resentment toward a relative about caregiving that was perceived as a problem by the caregiver. Semple (1992) views it as an overt interpersonal disagreement between caregiver and

family member by blood, marriage, or adoption. When developing a family caregiver conflict scale for stroke, Clark, Shields, Aycock, & Wolf (2003) defined family conflict as disagreements within the larger family system about various issues and/or needs (physical or emotional) arising during stroke recovery. A difficult factor in defining family conflict at the end-of-life is that "family" is typically defined broadly in palliative care, often with the patient defining it from their own perspective.

Conflicts may stem from family members' actions and attitudes towards caregivers and/or the patient as well as conflicts around definitions of the illness and strategies for care. Complicating the issue, divorce and remarriage have resulted in many large, blended families, which may encounter disagreements when care decisions become necessary (Wein, 2000). In her assessment of family conflict Gwyther (1995) distinguishes among four sources: 1) limits to the norm of solidarity—how long a family member can give care without a return for their investment, 2) family members disapproving of other members' actions or attitudes toward the patient, 3) disagreements about the nature and seriousness of the impairment and the most appropriate care, and 4) perceptions that less involved family members fail to appreciate the extent of the demands on primary caregivers or disapprove of the quality of family care being given.

Beyond caregiving studies that shed light on conflict in later life families, relatively little empirical attention has been given to family conflict specifically at the end-of-life. The Hospice Foundation of America certainly acknowledges family conflict as an issue in need of attention, having devoted two recent articles to it in its *Living with*

Grief series. In one, Beckwith (2005) discusses conflict from an ethical standpoint, citing various causes of conflict, universal issues families face that can trigger conflict, how advance directives can prevent conflict in some circumstances, and ways in which hospice can help. In the other, Sofka (2007) discusses a number of challenges families face when a member's death is imminent, as well as barriers to providing effective care and support during that time. Family conflict is cited as one challenge, with a number of potential contributing factors noted, such as blended and nontraditional families, generational differences in beliefs and traditions, diverse personalities and coping styles, and different relationships and histories with the patient. Though these articles present family conflict as a very real and natural part of end-of-life care, the claims and suggestions made by the authors have not been adequately researched. Further, the popular media and some researchers (Breen, Abernethy, Abbott, & Tulsky, 2001; Tilden & Tolle, 1995) have certainly drawn attention to conflict around decisions to withdraw medical treatment, with the 2005 Terri Schiavo case bringing awareness to the broader public. Families face additional stressors beyond such decisions, though, that can result in family conflict as they make other important decisions, cope with their impending loss, and manage the patient's care.

In a recent article, Lichtenthal & Kissane (2008) review the literature on family conflict in palliative care, identifying the prevalence, common sources, and assessment and intervention strategies. While this literature review represents increased attention to the issue of family conflict at the end-of-life, much of the research cited is not specific to

end-of-life and/or statements are mainly anecdotal. For example, the authors indicate that opportunities to accomplish potentially beneficial tasks such as addressing unfinished business, life review, and saying goodbye, may be thwarted by family conflict. They also indicate that mental health problems in a patient or family member can increase the likelihood of conflict and hinder resolution, though no research is cited to support this claim. Further investigation of the causes and effects of conflict is needed. Nonetheless, this review along with additional related studies, provide a starting point for understanding this complex phenomenon.

Several studies have touched on the issue of family conflict at the end-of-life, though it was typically not a central focus of the investigation and involved primarily professional perspectives. In one study involving families of cancer patients, the researchers found that disputes increased in frequency as patients approached death, as severity of illness was predictive of family strain (Sales, Schulz, & Biegel, 1992). A study examining nurse perceptions of supportive nursing behaviors in a hospital-based palliative care program identified family conflict as hindering the effective provision of family care (Bridgman & Carr, 1998). In another study nurses shared challenging practice incidents involved in palliative nursing, and the theme of conflict and control surfaced as a shared experience (Hart, Yates, Clinton, & Windsor, 1998). The participants repeatedly discussed their roles in mediating conflicted situations and described conflict within themselves, between themselves and others, or between others. In a study targeting physician perceptions, family conflict about the best course of action

was viewed as a major barrier to talking about preferences and providing quality end-of-life care (Kayashima & Braun, 2001). In a retrospective study of patient care at the end-of-life, Witzner, Moody, & McMillian (1997) found that family problems (43%) was cited as one of the most common problems experienced in a sample of 100 cancer patients. In an additional study involving hospice social worker perceptions, Arnold, Artin, Griffith, Person, & Graham, (2006) identified family stress/conflict as very often or often an unmet need at the time of admission in 67% of respondents, with this figure dropping to 28% during post-admission visit. "Family conflicts, struggles, and issues" were identified by 17% of respondents as a perceived reason for unmet needs and "family issues" were cited by 14% of the respondents as a perceived barrier to addressing unmet needs. The authors concluded that because family issues/conflict was cited as a barrier and as a reason for unmet needs, the role of the family in patient outcomes cannot be underestimated and assessment of family issues and dynamics is particularly important. In another study, 1,189 family caregivers were surveyed via telephone in an attempt to examine the end-of-life experiences of elders dying in community settings and their family caregivers (Tilden et al., 2004). They were administered a questionnaire involving questions regarding advance directives, use of life-sustaining treatments, hospice enrollment, decedent symptom experience and perceived stress, family financial hardship, out-of-pocket expenses, and caregiver strain. Among other findings, the researchers discovered that stress and conflict among relatives can be reduced when family members formulate an advance care plan. Conflict most often erupted regarding

who exactly comprised the family and/or who held decision-making authority.

Kramer and colleagues have begun an interesting line of research with family conflict at the end-of-life as a central focus. An examination of the perspectives of end-of-life professionals in a managed care program resulted in the first model of family conflict at the end-of-life (Kramer et al., 2006). Survey, interview, and focus group data of interdisciplinary professionals working in a fully integrated managed care program for low-income elders with advanced chronic disease were utilized. The conceptual model of family conflict at the end-of-life included the following components: (1) family conflict, (2) family context, (3) conditions, (4) contributing factors, (4) intervening processes and (5) consequences (see Appendix 1 for additional details). The results of this study suggest that family conflict is common at the end-of-life, is a multidimensional construct, takes place within the context of family history and relationships, and is fueled by factors that arise as death comes into awareness for the patient, family, and health care team. It has potentially adverse consequences such as impeding timely and appropriate care planning and implementation, patient self-determination, quality care, teamwork, emotional and spiritual well-being, and continuity of care. Kramer et al. (2009) have recently continued this line of investigation, examining the correlates and predictors of family conflict reported by 155 spouses and adult children of persons with lung cancer involved in a cross sectional statewide survey. Findings include significant bivariate correlations between family conflict and family context variables (i.e. history of conflict, younger respondent age, race, and specified end-of-life care wishes of the patient),

conditions (i.e. greater physical and physiological clinical care needs of the patient), and contributing factors (i.e. communication constraints and family asserting control). In the multivariate model, significant predictors of family conflict included prior family conflict, race, communication constraints, and family members asserting control, with the model explaining 72 percent of the variance in conflict.

A number of factors may contribute to conflict for families involved in end-of-life care, such as advances in medical technology that complicate the process of end-of-life decision-making, the low completion rates of advance directives, longer life expectancies, a lower infant mortality rate, farther geographic proximity for many families, lack of a widely accepted ethical and legal framework regarding when to terminate life-sustaining treatments, and substantial differences in age, culture, social class, and education between physicians and families (Bowman, 2000). These factors contribute to an increased need for health care system and family negotiation, increased differences in perspectives and options, and end-of-life experiences filled with challenging decisions (Bowman, 2000).

As indicated, most studies involving family conflict at the end-of-life have focused on professional perspectives and/or have not attended to family conflict as a central thrust of the investigation. This preliminary research suggests that family conflict at the end-of-life is an important issue for patients, families, and professionals, but that further investigation of this potentially complex phenomenon is needed. Sherman (1998) expresses the significance of family conflict at the end-of-life in the following statement:

> When facing the terminal illness of a relative, the suffering extends to every member of the family as a unit in some way. Family members often spend considerable time reviewing painful aspects of the past with feelings of regret for disagreements, conflicts, or failures and a wish that relationships with the patient and with each other were somehow different. With each family member's unique experience of the stress, families may find it difficult to pull together to effectively cope with the imposed life changes. In families where communication is indirect, little agreement about the nature of the problem may exist, and roles may be rigidly entrenched, resulting in conflict with regard to the delegation of the role responsibilities formally assumed by the ill family member. The dynamics of families in times of crisis may exacerbate a lack of tolerance for differences in opinion. Additional conflict also may occur when family members differ in their preferences for the location of care (p.359).

Death Anxiety

How people view death may affect how they conduct their lives (Wong, Reker, & Gesser, 1994). It has been said that Americans live in a "death denying" or "death avoiding" society that views death not as a natural event, but as a "medical problem" to overcome (Walsh, 2002). Results of a recent survey of over 3000 Idaho residents over the age of 35, for example, indicated that approximately 30% were very or somewhat afraid of dying, 67% were somewhat or very afraid of dying from a long term illness, and 73% were very or somewhat afraid of dying painfully (Simpson-Whitaker, Totten, & Moffat-Miller, 2006). The belief that the medical profession can prolong life indefinitely has encouraged denial of mortality and resulted in people being unprepared to face death (Ita, 1995). Levine et al. (1987) define denial as a lack of awareness of, or ability to, recognize or discuss the patient's illness, diagnosis, and terminality, despite being informed of it. Kubler-Ross (1969) has described denial as a normal human response to grief. Studies have also suggested that it is a common initial response to life threatening

illness among patients (Hackett & Cassem, 1974; Levine et al., 1987; McIntosh, 1976) and their significant others (York, 1987). Miller (1991) discusses how patients and family members vacillate back and forth between denial and acceptance and feelings in between. Wong, Reker, & Gesser (1994) discuss how fear of death, death acceptance, and death avoidance relate to well being and the pursuit of personal meaning.

Studies have suggested that denial can be functional as well as have adverse outcomes. Epperson (1977), for example, cites the role of denial in providing the patient and family with a sense of hope that is needed to carry on. Denial can be used as an anti-anxiety mechanism during a time of crisis that can be used temporarily to cope until the reality of the situation can be acknowledged and accepted (Hackett & Cassem, 1974; York, 1989). Denial has also been identified as disruptive, though, when it goes beyond the function of a temporary coping mechanism and leads to people making inappropriate treatment decisions, avoiding preparations for death, or avoiding responsibility (York, 1989). Studies have revealed, for example, that primary caregivers who were in denial of the patient's terminality were more likely to place their loved one in an inpatient setting rather than continue care at home as planned (Ita, 1994; Reese, 2000). Additional studies have noted that denial results in inappropriate treatment or care, noncompliance with treatment plans, poor health outcomes for patients, and interference with patient self-determination (Leavitt, 1990; Mandel, 1982; Prigerson, 1992; Reiss & Gonzales, 1986; Schonwetter, Walker, & Robinson, 1995; York, 1987).

Though hospice patients document their recognition of terminality and acceptance

of palliative care, primary caregivers and other family members may use denial of the patient's terminality as a coping mechanism (Reese, 2000). Family members may be at varying levels of death acceptance and denial and their feelings may manifest in different ways. In a study of patients with advanced cancer, for example, Martens & Davies (1990) found that caregiving spouses described the death of the patient as uncertain even when the patient perceived it as inevitable. A prevalent belief exists in the hospice field that intervention with denial is risky (Connor, 1992) in that patients and families need to approach death on their own terms. Though this may be the case, individual attitudes and feelings about death may have a significant impact on family relationships and care provision.

Intervention with Families at the End-of-Life

General agreement exists that families have information, education, training, health, and mental health needs of their own that should be attended to. Interventions discussed in the literature and utilized by end-of-life professionals include discussing advance directives and preferences regarding where to die; preparing for death both emotionally and practically; dealing with unfinished business; resolving family-patient conflicts; alleviating emotional and spiritual suffering through active listening, meaningful presence, and the teaching of healing strategies such as relaxation, imagery, or mediation; respecting family caregivers' knowledge of patient needs; encouraging family caregivers to participate in all aspects of patient care; acknowledging caregiver efforts; encouraging the expression of fears, concerns, loss, and grief; connecting to

respite and other services; problem-solving; and conducting family meetings (Sherman, 1998). Common services utilized by families with a dying member include hospice, home health care, inpatient care, respite, transportation services, meal programs, homemaker services, senior centers, and adult day care (National Hospice and Palliative Care Organization, 2006). While most of these services and interventions are directed at meeting patient needs, professionals assume they enhance family members' well-being as well.

Though there has been increasing awareness that intervention for the whole family is the best approach to be adopted in a palliative care service (Cassileth & Hamilton, 1979; Greene, 2000; Northuse, 1984; Rait & Lederberg, 1989; Bluglass, 1991; Baider et al., 1996; Lederberg, 1998), intervention research specifically pertaining to families at the end-of-life is lacking. This deficiency may be related to the barriers inherent in implementing family interventions within palliative care settings (Hudson et al., 2004). In hospice, one such barrier is receiving referrals early enough to be able to get to know the patient and family, assess needs, and intervene before the patient's death (Arnold et al., 2006). Several interventions specific to families involved in end-of-life care have received attention in the research literature, though. First, Allen & Shuster (2002) note that comprehensive familial advance planning evaluations and functional capacity assessments assist families in making the transition to end-of-life. Similarly, Ditto et al. (2001) suggest that advance care planning eases the minds of patients, caregivers, and family members. Second, Noble & Jones (2005) suggest that narrative

therapy is helpful in supporting the family of a terminally ill patient who is "finishing business." Narrative approaches focus on storytelling, giving participants the opportunity to examine and make meaning of their lives. Third, Allen, Haley, Roff, Schmid, & Bergman (2006) present two community-based, problem-solving intervention projects that target family caregivers for individuals with various stages of life-limiting illnesses. Fourth, the importance of family meetings has been discussed as helping families cope and obtain the right resources to care for their dying relative (Lichtenthal & Kissane, 2008; Miller, Kretch, & Walsh, 1999). Fifth, Multiple-family Groups, which allow families to come together, receive education, and have the opportunity to connect with other families, have been cited as enhancing the coping of family members involved in difficult situations (Steinglass, 2000).

Research focused on helping families prevent or abate the negative impacts of conflict at the end-of-life is virtually non-existent. This may stem, in part, from the fact that clinicians are not well trained to manage conflict (Lichtenthal & Kissane, 2008), or believe that conflict is best avoided or suppressed in order to keep the peace (Back & Arnold, 2005). While empirical studies suggest that ethics consultations can help deal with difficult conflicts (Dowdy, Robertson, & Bander, 1998; Schneiderman et al., 2003), these studies have focused mainly on the use of futile medical treatments, whereas family conflict often involves other factors as well. One approach, Family Focused Grief Therapy (FFGT) has been suggested as an effective intervention specific to managing disagreements, optimizing family functioning, and promoting the sharing of grief (Eunice

et al., 2004; Kissane, 2000; Kissane et al., 2006; Lichtenthal & Kissane, 2008). This proactive approach, which can begin during palliative care and continue beyond the patient's death, is designed for families who are at risk for poor functioning before and/or after the patient's death. Additional approaches for preventing and/or addressing conflict have been cited in the literature, but need to be more rigorously investigated and/or applied specifically to end-of-life (Back & Arnold, 2005; Dubler & Marcus, 1994; Goold, Williams, & Arnold, 2000; Kramer & Auer, 2005; Kramer et al., 2006; Levine & Zuckerman, 1999). An aim of the present study was to identify approaches used by hospice professionals to address family conflict as a foundation for further investigation. It seems logical that families facing an end-of-life situation can be influenced to come together, and that the palliative and end-of-life phase may provide opportunities to resolve conflict and to optimize family functioning (Kissane, 2000).

Hospice

The first hospice program in the United States was established in New Haven, Connecticut in 1974. Enrollment in hospice in the U.S. has risen from about 1,000 per year in 1975 to 1.2 million 2005 (National Hospice and Palliative Care Organization, 2006). In fact, in 2005, approximately one-third of all deaths in the United States were under the care of a hospice program (National Hospice and Palliative Care Organization, 2006). This increase is largely due to congressional approval of hospice care as a separate Medicare benefit in 1982, which essentially caused hospice to become a covered benefit for the vast majority of dying Americans (Last Acts, 2002). Medicare covers

almost every person age 65 and older and 75 percent of people who die are in that age group (Last Acts, 2002). Today there are more than 4,100 hospice programs in the United States, Puerto Rico, and Guam (National Hospice and Palliative Care Organization, 2006).

Hospice is a program that provides care to people who have a life limiting or terminal illness or injury. Most reimbursement sources, and therefore most hospice programs, require an anticipated life expectancy of 6 months for a person to enroll. Hospice is available for people of all ages, though the majority of those served are older adults. People diagnosed with any terminal condition are eligible, though the majority of patients enrolled have a cancer-related diagnosis. The goal of hospice care is palliation; interventions are not curative in nature but are designed to enhance comfort, lessen pain and other symptoms, and support patients and their families. Hospice care neither prolongs life nor hastens death, but simply strives to improve the quality of a patient's final days by offering comfort and dignity and respecting patient wishes. The philosophy of hospice involves the belief that everyone has the right to die pain-free and with dignity (Hospice Foundation of America, 2006).

Hospice is family-centered, working closely with the patient's family to manage care and to respond to the emotional, social and spiritual impact of the disease on family members and friends. In hospice, families are both the recipients and the providers of care (Corless & Nicholas, 2003). The patient and family are viewed as being the "unit of care," and a "primary caregiver" is appointed to work most closely with the patient and

the hospice team, helping to make decisions when appropriate. Hospice helps to coach/guide the primary caregiver and others on how to care for the patient, supporting patients' and their families' efforts to remain together when desired (Raleigh, Robinson, Marold, & Jamison, 2006).

Hospice services are most often covered by Medicare (Medicare Hospice Benefit), since more than 90 percent of the hospices in the U.S. are Medicare certified. Eighty percent of people who use hospice are over age 65 and are entitled to the services offered under the Medicare Hospice Benefit. Since this benefit covers almost all aspects of hospice care, there is little out-of-pocket expense to the patient and/or family. Medicaid (Medicaid Hospice Benefit) offers similar coverage in 47 states and the District of Columbia. Many private insurance companies also cover hospice, though the extent of coverage can vary dramatically from mirroring the Medicare Hospice Benefit to paying only for certain supplies and/or services. Some hospices have a private pay and/or pro bono option for those without insurance. Medicare requires a set of hospice core services, and hospices are required to provide this set of services to each patient they serve regardless of insurance status or ability to pay (Hospice Foundation of America, 2006; National Hospice and Palliative Care Organization, 2006; Wisconsin Department of Health and Family Services, 2005).

Because people with terminal illnesses often live in a variety of settings from the time they are diagnosed until the time they die, hospice encourages continuity of care by following a patient from setting to setting (Fort Cowles, 2000). Most hospice care takes

place in the patient's residence or that of a loved one. In fact, the utilization of hospice services has been shown to substantially increase the chance of dying at home for people of all ages (Mezey, Dubler, Mitty, & Brody, 2002; Moinpour & Polissar, 1989; Weitzen, Teno, Fennel, & Mor, 2003). "Home" is defined by the patient and may include nursing homes, community based residential facilities, adult family homes, or other settings. Some programs also operate hospice centers and/or inpatient units. Accordingly, hospice provides care at four different levels: routine home care, general inpatient, continuous home care, and respite. Routine home, by far the most common form utilized (95.8 %) involves intermittent care in the patient's residence, a group home, or a nursing facility (National Hospice and Palliative Care Organization, 2004). General inpatient care is used when the patient needs hospitalization, typically due to uncontrollable symptoms or family crisis. When this type of care is used, hospice works with the inpatient provider to develop a plan of care and visit the patient every day. Continuous home care is very rare and involves extended nursing care in the patient's residence, typically due to uncontrollable symptoms and/or intense care needs that the family cannot manage. Respite care involves a "break" for the caregiver in which the patient is placed in a facility, generally the hospital, for up to five days.

The care provided by hospice programs is holistic and individualized—it addresses the psychological, social, spiritual, and physical needs of the patient (Hospice Foundation of America, 2006). To provide this care, hospice programs employ and/or contract with an interdisciplinary team of professionals including nurses, social workers,

spiritual counselors, bereavement counselors, nursing assistants, dieticians, and therapists. A medical director (physician) works with the team to determine appropriate care and resolve challenges. Most often, the patient's own physician is also involved in care planning. These professionals work as a team to provide pain and symptom management, personal hygiene maintenance, emotional and spiritual counseling, bereavement support, and physical, occupational, and speech therapy as needed. Additional services offered include medications, medical supplies, equipment, and volunteer support. Hospice team members make regular visits to the patient and his or her family, with frequency determined according to need and regulations. On-call services, usually provided by a nurse, are available 24 hours a day, seven days a week. According to Fort Cowles (2000), "the interventions provided by hospice workers emerge from a developing body of theory and knowledge about such issues as the nature of suffering and the control of pain; healthy and unhealthy grief and bereavement; the interaction and interdependence of mind, body, social and cultural environments, and spiritual needs; the family as a system; and the etiology and modification of a person's sense of locus of control" (p. 254).

The role of social workers in hospice is more clearly defined than in other palliative care settings because hospice legislation insures social work inclusion. Hospice social workers' specific functions include the psychosocial assessment of patient and family and the development of a care plan that stems from this assessment. In addition, they provide individual and family counseling before and after the patient's death. The

social worker also arranges for additional services from other community and governmental agencies as needed, and provides case management when indicated (Center to Advance Palliative Care, 2004). Social workers address a number of patient and family issues in hospice including, but not limited to: 1) admission and adjustment to hospice, 2) admission and adjustment to additional programs and care settings, 3) adjustment to the diagnosis, prognosis, and/or care plan, 4) lack of information to make informed decisions and maintain control, 5) lack of needed supportive services, and 6) barriers to discharge from hospice and/or a care setting (Fort Cowles, 2000). These issues bring with them a variety of patient and family needs at the practical, physical, emotional, psychological, and spiritual levels. Hospice social workers have the main function of maximizing the adjustment of hospice patients and their families to the challenges they face by serving in the roles of broker, liaison, problem-solver, administrator, counselor, educator, lobbyist, and program planner (Richman, 1995). Specifically, they provide supportive counseling, patient and family advocacy, education about the disease process, assistance with advance directives completion and planning for the future, organization and scheduling, coordination of and referral to other community programs, assistance with group home and nursing home placement, spiritual support, coordination of family meetings, facilitation of family communication, and legal and financial consultation. The connections that social workers make with patients and families in hospice provide opportunities for social workers to empower, educate, and assist in achieving goals to create meaning at the end of life (Christ & Blacker, 2005; Luptak, 2004; Taylor-Brown &

Sormanti, 1988). In their survey of 391 health care social workers, Csikai & Raymer (2005) assessed educational content and skills needed for competence in practice with those facing the end of life. Content perceived as most needed included psychosocial and social needs of patients and families, psychosocial interventions to ameliorate distress, and the influence of dying on family dynamics. Skills perceived as essential for competence in end of life care practice included assessing complex needs of patients and families, communication of psychosocial needs to team members, facilitation of effective family and team communication, and provision of crisis intervention.

Although social work has been slow to empirically measure its contributions to hospice and palliative care preliminary studies have suggested positive effects (Mahar, Eikman, & Fry, 1997; Reese, Raymer, & Richardson, 2000; Sherin, 1997; Silberstein, 1998). Studies have demonstrated that increased social work services in hospice and home health are related to reduced costs. Cost savings relate to decreased hospitalizations, on-call visits, nursing visits, use of pain medications, and use of IVs, and additional effects include increase in patient and physician satisfaction, higher quality of life for patients, and decrease in staff turnover due to greater job satisfaction.

Though hospice has mainly been evaluated with respect to patient outcomes, studies have suggested that hospice benefits family caregivers as well. In two related studies involving hospice caregivers, McMillan & Mahon (1994a/1994b) found that patient quality of life was increased after enrollment in hospice, patient and caregiver quality of life were positively correlated, and caregiver quality of life was maintained

during the first month of hospice care. In a study involving 21 recently bereaved family caregivers of hospice patients, Raleigh et al. (2006) found that subjects repeatedly identified the importance of hospice support in making the decision to keep the patient at home and in making home care a reality. Subjects frequently noted that hospice workers made them feel highly cared for, respected, and supported. The more contact caregivers had with hospice, the fewer coping strategies they needed to employ. These findings are consistent with others suggesting that hospice plays a significant role in the dying process and in promoting adaptive responses in caregivers (Newton et al., 2002; Hull, 1993; Goldstein et al., 2004). In a study designed to evaluate the dying experience at home and in institutional settings from family members' perspectives, Teno et al. (2004) found that family members of patients receiving hospice care were more satisfied with the overall quality of care compared to those dying in an institutional setting or with home health services. Family members of those who received home hospice care were more likely to report a favorable dying experience. Connor, Teno, Spence, & Smith's (2005) study involving a web-based survey of family members suggests, though, that hospice has room to improve with respect to meeting family needs. Though respondents rated their overall satisfaction with care very highly, they identified opportunities for improvement with respect to attending to family needs for support and communication.

Hospice in Rural Areas

In 2003, 48 million people lived in rural communities across the country, a 10 percent increase since 1990 (National Advisory Committee on Rural Health and Human

Services, 2004). The emigration of younger people to urban areas, coupled with lower immigration rates and influxes of retirees into rural areas, have resulted in an older population base in many rural communities (Murty, 2001; National Advisory Committee on Rural Health and Human Services, 2004). Approximately 25 percent of all elders live in rural areas and the population of rural America is becoming older (National Advisory Committee on Rural Health and Human Services, 2004; National Rural Health Association, 2001). Policy-makers, practitioners, and researchers are becoming increasingly aware of the challenges associated with meeting the complex health and social needs of rural older Americans (National Rural Health Association, 2001). An analysis of the literature on end-of-life care in rural areas suggests eight general challenge areas for rural communities and providers.

First, trends in service delivery have impacted hospice organizations, altering the way in which care is provided to rural residents. Consolidation, regionalization, and centralization have resulted in the creation of large rural service areas covering many counties (Murty, 2001). Pressures toward large scale production, specialization, and efficient use of the time of specialists have pressured programs to provide services in central locations to improve the productivity and efficiency (Murty, 2001). Rural communities are often located at a distance from population centers, so these service delivery changes result in difficulties with transportation, costs, communication, and service coordination (Murty, 2001). Further, service providers located in a central office of a region often do not have an in-depth understanding of the outlying communities and

may be viewed as outsiders by residents (Murty, 2001).

Second, a number of financial issues exist that place rural communities at a disadvantage in providing end-of-life care. At the consumer level, people living in rural areas are more likely to be living in poverty and be uninsured than those living in urban areas (National Advisory Committee on Rural Health and Human Services, 2004; National Rural Health Association, 2001; Rogers, 2002). This not only impacts the dying individual and their family, it impacts hospice programs, which often provide care for a reduced cost or free of charge to those who lack insurance. For programs serving an area with a high number of uninsured consumers, this arrangement can be a financial burden. At the provider level, hospices are more vulnerable to the trends affecting the entire hospice industry, such as shorter lengths of stay, increasing medication and product expenses, and costly procedures (Casey, Moscovice, Virnig, & Kind, 2003; Huskamp, Buntin, Wang, & Newhouse, 2001). Medicare hospice per diem rates tend to be lower for rural hospices than urban ones (Huskamp et al., 2001; Virnig, Moscovice, Durham, & Casey, 2004), and rates are not adjusted for differences in cost that may be significantly higher for rural programs such as travel expenses and staff time needed to get to patients (DeCourtney, Jones, Merriman, Heavener, & Branch, 2003; Huskamp et al., 2001; Virnig et al., 2004). Rural hospices are less likely to have contracting arrangements with distributors to purchase lower-cost goods for patients, and do not have as much financial flexibility to absorb the costs of patients with expensive needs (Huskamp et al., 2001; Virnig et al., 2004). Rural programs tend to have a low volume of patients using

services, resulting in low levels of revenue coupled with the need to staff for the required 24 hour per day, 7 day a week staff availability (Virnig et al., 2004). It is difficult for programs to spread out fixed costs across a small number of patients (Virnig et al., 2004). With the first and last days of hospice being the most expensive, rural hospices don't have as much financial flexibility to survive the trend associated with short lengths of stay (Huskamp et al., 2001).

Third, rural areas are disproportionately affected by Medicare and Medicaid policies, with rural providers struggling to survive in today's reimbursement climate (National Rural Health Association, 2001). For example, regulations have made it difficult for some small rural hospices to obtain and maintain Medicare certification due to rules regarding how quickly the hospice needs to be able to respond to a patient call (DeCourtney et al., 2003; Virnig et al., 2004). Medicare certification is vital to hospices for reimbursement and recognition purposes. The inability of some hospices to meet the regulations has lead to some geographical areas going un-served or inadequately served by a hospice or palliative care program. Several authors talked about this being especially problematic for rural-dwelling native communities (DeCourtney et al., 2003; Finke, Bowannie, & Kitzes, 2004; McGrath, 2000).

Fourth, the remoteness of the location compounded by the mobility of the population can make access to health providers and hospice care more challenging and costly for rural dwellers (McGrath, 2000; Rogers, 2002). The hospice rate use for rural areas is only about 75 percent of that of urban areas (Virnig et al., 2004) and as such rural

dwellers are less likely to achieve a home death (Mezey, Dubler, Mitty, & Brody, 2002; Moinpour & Polissar, 1989; Tolle et al., 1999; Weitzen et al., 2003). It can be costly for rural hospice programs to transport patients to inpatient facilities, nursing homes, and clinics when such care is needed (DeCourtney et al., 2003). It may also be uncomfortable, painful, or exhausting for a patient to travel far distances to receive care. Transportation can be especially problematic when weather and road conditions are bad, both in terms of patients getting to out-of-home services and hospice professionals reaching patients in their homes (DeCourtney et al., 2003; McGrath, 2000). This issue can lead to feelings of patient and family uneasiness with hospice response times and can result in issues of professional safety and isolation for the hospice staff.

Fifth, many rural areas lack health and social services that would be considered standard in urban or suburban settings, resulting in fewer available programs to share in the care of someone with a terminal diagnosis (National Advisory Committee on Rural Health and Human Services, 2004; National Rural Health Association, 2001; Rogers, 2002). The smaller economies of scale, higher costs of developing and providing services, and lower supply of critical health personnel handicap the development of adequate long-term care services in rural areas (Rogers, 2002). Programs and policies that do exist are often "scaled down" urban models that do not account for the unique needs of rural residents (National Rural Health Association, 2001). Adult day care, respite, home delivered meals programs, volunteer services, and community-based residential facilities are less readily available (Casey et al., 2003; National Advisory

Committee on Rural Health and Human Services, 2004). Medicaid-financed home and community-based services waiver programs, which promote alternatives to nursing home placement, are limited in scope and geared toward urban areas (National Rural Health Association, 2001). The lack of community-based alternatives to nursing home care has resulted in a disproportionate share of nursing home beds existing in rural areas, an increased likelihood of nursing home admission (National Rural Health Association, 2001; Rogers, 2002). People living in some rural areas have an increased likelihood of dying in a nursing home or hospital, away from family, friends, and familiar surroundings, because of a lack of local resources (DeCourtney et al., 2003; National Advisory Committee on Rural Health and Human Services, 2004; National Rural Health Association, 2001).

Sixth, the pool of available informal and formal caregivers is smaller in rural areas. As increasing numbers of young people leave rural areas for urban settings, a shortage of informal caregivers is occurring. Rural areas have more of a difficulty getting volunteers to come in from other communities due to distances and concerns about safety and isolation. Rural areas tend to have a smaller existing pool of professional and administrative resources (Finke et al., 2004; McGrath, 2000), and rural providers struggle with recruiting and retaining licensed, trained health professionals (National Advisory Committee on Rural Health and Human Services, 2004; National Rural Health Association, 2001; Rogers, 2002). The nursing shortage has significantly affected rural communities, as nurses are drawn to the larger cities for higher pay, more opportunities

for advancement, and socialization/recreation (Commission on End-of-Life Care, 2000-2001). This can hinder hospice programs' abilities to account for the necessary 24 hour per day, 7 day per week staff coverage (Casey et al., 2003). There is a shortage of physicians who are willing to practice directly in rural areas, so oftentimes patients will have to travel far distances to see a doctor or will have limited opportunity to interact with a visiting physician (Commission on End-of-Life Care, 2000-2001; Rogers, 2002). Staff turnover rates tend to be higher in isolated areas, as professionals feel isolated or stagnated and move on to other opportunities (DeCourtney et al., 2003; National Rural Health Association, 2001). Those who do practice in rural areas are often at a disadvantage in terms of training and educational opportunities and may lack training in palliative care (McGrath, 2000).

Seventh, a lower level of service awareness exists among elders and service providers in rural areas (National Advisory Committee on Rural Health and Human Services, 2004; National Rural Health Association, 2001). There tend to be fewer end-of-life advocates in rural areas who can educate people and connect them to useful resources (Commission on End-of-Life Care, 2000-2001). Rural areas are less likely to benefit from media campaigns, educational offerings, and outreach efforts (Tolle et al., 1999). Some hospices that serve rural areas are located in an adjoining city and are likely to market mainly within the city. Therefore, residents are less likely to know about hospice as an option. Even if they do know about hospice and other resources, they may be less inclined to use them. One study suggested that rural families do not ask for information

because they do not want to be perceived as abusing the system (Wilkes, White, & O'Riordan, 2000).

Eighth, the infrastructure of many rural communities can create challenges in the provision of end-of-life care. Rural areas tend to have a more limited communications infrastructure (Finke et al., 2004). There may be limited phone access, cell phone service, and computer access (McGrath, 2000). Hospice providers may find this challenging when trying to respond to patient needs. Many rural areas lack the capability to support the maintenance of sophisticated medical equipment (McGrath, 2000). With more and more patients utilizing such equipment at home to avoid institutionalization, these limitations can put rural residents at a significant disadvantage. Housing conditions tend to be poorer and sanitation more of a problem in rural areas (National Advisory Committee on Rural Health and Human Services, 2004). This can create safety issues for the medically vulnerable patient and for the hospice staff (McGrath, 2000).

As indicated, the existing literature portrays a rather grim outlook for people dying in rural areas to receive quality end-of-life care. Very little published work exists on this topic, and the existing work is very problem-focused, identifying deficiencies in the delivery of end-of-life care (Evans, Stone, & Elwyn, 2003). A recent study conducted by Haxton & Boelk (in press) suggests that despite the challenges rural communities face, social workers are already utilizing a number of creative solutions, tapping into perceived community strengths, that can be built upon to yield high quality end-of-life care for patients and families. Recently published textbooks about rural communities have also

taken a more positive approach, calling for practitioners and policymakers to build on the assets that exist at the individual, family, and community levels (Butler & Kaye, 2004; Carlton, Edwards, & Reid, 1999; Ginsberg, 1998; Jones & Zlotnik, 1998; Scales & Streeter, 2003). The idea behind asset-building as a strengths-based approach is that communities have the capacity to respond to their own challenges and to assist individuals and families who live there when they need help (Murty, 2004). Rather than focusing only on the needs and challenges associated with a given community, this approach stresses finding the resources that it has to offer, the ways it resolves problems, and how it provides assistance to residents in need (Murty, 2004).

Rural communities have many values and characteristics that can be drawn upon to promote quality, patient and family directed end-of-life care. Self-reliance, independence, practicality, community, cooperativeness, sociability, hard work, religion, responsibility, and family appear to be of central importance to many rural dwellers, particularly elders (Dorfman, Murty, Evans, Ingram, & Power, 2004). Rural areas are known for their tightly knit, interdependent, dense social networks in which people know one another in multiple ways (Murty, 2004; Watkins, 2004). These networks can make the coordination of care among formal service providers easier (Casey et al., 2003). Many rural communities have a tradition and perception of communal responsibility (Murty, 2004; National Advisory Committee on Rural Health and Human Services, 2004). Strong local organizations and institutions such as churches, youth groups, special interest clubs, and service organizations exist in many rural areas and can be instrumental

in generating awareness, funding, and collaboration for end-of-life care (Murty, 2004). Further, most rural communities have a few easily identifiable active community leaders who can be called upon to design, develop, implement, and promote projects, programs, and policies that enhance end-of-life care (Murty, 2004).

Cultural Perspectives

The United States is becoming more and more diverse, and research suggests that end-of-life experiences vary according to racial/ethnic/cultural factors that influence needs, attitudes, preferences, practices, service availability, decision-making, and service provision (see Blackhall et al., 1999; Blevins & Papadatou, 2006; Braun, Pietsch, & Blanchette, 2000; Fort Cowles, 2000; Gordon, 1996; Morgan & Laugani, 2002; Noggle, 1995; Parry & Ryan, 1995; Talamantes Lawler, & Espino, 1995; Werth, Blevins, Toussaint, & Durham, 2002 for useful reviews). Though characteristics such as age, gender, sexual orientation, disability, and health status may influence a person's social reality, care preferences, decisions, and behaviors in the face of death, much of the existing research has operationalized culture as ethnicity, religious affiliation, or geographic region (Blevins & Papadatou, 2006). Most studies compare African American and White caregivers and focus almost exclusively on Judeo-Christian spiritual traditions (Allen et al., 2006). According to one literature review, most of the literature on cultural issues at the end-of-life can be divided into two major categories: 1) general discussion or review articles on one or more particular cultural dimensions and 2) empirical studies investigating one or more cultural dimensions (see Blevins & Papdatou,

2006 for a summary of recent publications). Additional research is needed to specify the pathways by which race, ethnicity, and culture affect the caregiving experience for individuals and families (Turner et al., 2004).

Researchers have identified four core value categories related to how death and bereavement are perceived and dealt with in different cultures (see Parkes, Laungani, & Young, 1997 for additional details). First, the individualism-collectivism spectrum contrasts the value of giving priority to one's personal goals over those of one's group versus giving priority to community and family goals over one's personal goals. It is thought that caregivers who belong to groups with higher levels of collectivism may experience less caregiver burden, as caregiving is viewed as a more natural part of family life (Knight et al., 2002). Second, the free-will-determinism category contrasts cultures that assume that each person has full responsibility and control over his or her actions with cultures that believe that an individual's life is controlled by higher forces. Third, the materialism-spiritualism category highlights that materialistic cultures hold the prevailing belief that a material world does exist in which phenomena can be explained in a pragmatic and observable way, whereas spiritual cultures entertain both material and supernatural explanations. Fourth, the cognitivism-emotionalism spectrum contrasts cultures that use rationality, logic, objectivity and control to focus on work, activity, tasks, and goals with cultures that are more relation-oriented, supporting open expression of feelings.

Cultural differences in values and practices have significant implications for

families and caregivers. Differing value orientations may lead individuals and families of contrasting cultures to experience and respond to death in ways that may not be congruent with dominant approaches in the U.S. health care system. For example, the health care system's emphasis on patient autonomy contrasts with preferences for more family based decision-making models appreciated by some cultures (Blevins & Papadatou, 2006; Searright & Gafford, 2005). Lower rates of advance directive completion among some groups may be somewhat influenced by cultural factors and family dynamics. Many cultures believe that communities and families, not individuals alone, are affected by life threatening illnesses and the accompanying medical decisions (Searright & Gafford, 2005). Additional points of cultural diversity relevant to end-of-life care include how family is defined, views on appropriate gender roles, how care is provided to older adults, views on marriage and relationships, and patterns of communication (Searight & Gafford, 2005).

One outcome associated with these differences is that hospice care is underutilized by persons of color. Though racial and ethnic minority populations comprise larger and larger proportions of the U.S. population every year, they are underrepresented in hospice programs. According to the National Hospice and Palliative Care Organization (2006), 82% of hospice patients were white in 2005. Those racial and ethnic minorities who do use hospice are often faced with challenges in getting their needs met within the context of their cultural beliefs and practices. Fort Cowles (2000) identifies five concrete ways in which cultural variations can influence hospice care: 1)

customs concerning whether to inform the patient and his or her family that the condition is terminal, 2) attitudes regarding the use of various types of medicines, both traditional and folk, 3) perceptions of what sort of physical environment would be best for death to take place in, 4) religious implications for encouraging the patient and family to express anxieties, concerns, questions, and other feelings, and 5) attitudes concerning efforts to prolong life and/or facilitate death when a person is in severe pain and death is inevitable.

Despite differences in culture, Blevins & Papadatou (2006) theorize that all humans share a number of common needs in the face of death. First, it seems that people of all backgrounds have a need for information, though the context and patterns by which it is shared may differ. Second, all people have a need to attribute meaning to suffering, life, dying, and death, though the systems of meanings attributed may be different. Third, all people need to maintain a sense of dignity and ensure a "good death," though each culture has its own definitions and means by which a "good death" should be realized. Fourth, people of all backgrounds have a need for care and support in the face of death, though the nature of the care they receive and preferences for care site may differ. Such similarities and differences across cultures have important implications for end-of-life research and care.

The African American community provides a good example of how families respond differently to end-of-life caregiving. Haley's stress-process model (Haley, Han, & Henderson., 1998; Haley et al., 1995) suggests that African American caregivers possess certain stress-buffering mechanisms (due to being more acquainted with stress

throughout their lives) that allow them to experience less negative outcomes than white caregivers. Studies comparing African Americans to Whites report differences in demographic characteristics, predictors of role strain, coping strategies, and levels of burden (Dilworth-Anderson, Williams, & Gibson, 2002; Koenig, 1997; Nkongho & Archbold, 1996; Williams & Dilworth-Anderson, 2002).

In general, African Americans are far less likely to receive psychological and counseling services to manage the illness through its course and to prepare for end-of-life (Corbie-Smith, Flagg, Doyle, & O'Brien, 2002; Crawley et al., 2000). They tend to rely more exclusively on family care than do Whites, who are more likely to utilize some combination of family care and formal care (Crawley et al., 2000). Investigations of the lower usage of formal care among African Americans have noted a greater reliance on filial piety, greater availability of extended family supports, tendencies towards keeping family matters private, difficulty justifying the use of community services which are not part of cultural traditions, and cultural beliefs that one should take care of one's own (Johnson, 1995; McCallion, Janicki, & Grant-Griffin, 1997; Turner et al., 2004). Formal care is complicated by the distrust that many African Americans hold toward the health care system, which has resulted from years of exclusion, racism, and discrimination (Turner et al., 2004). African Americans are more likely than whites to prefer aggressive treatment during the terminal phase of an illness, one-third as likely to have living wills, and one-fifth as likely to have do-not-resuscitate orders (Degenholtz, Arnold, Meisel, & Lave, 2002).

With respect to hospice use, African Americans comprised only 7.4 % of hospice patients served in 2005 (National Hospice and Palliative Care Organization, 2006). Studies have reported numerous barriers to African Americans utilizing hospice care, including philosophical differences regarding the use of life-sustaining measures; cultural mistrust of the health care system; the strong roles of culture; the preference avoid going outside of the family for help with medical caregiving; lack of knowledge about hospice; the view that use of hospice equates to giving up hope; religious and spiritual views that result in fear of the dying process and validation of suffering as a part of spiritual commitment; socioeconomic status; and lack of health insurance (Taxis, 2006). In a qualitative study exploring the perceptions and experiences of African Americans regarding end-of-life care and participation in hospice programs, Taxis (2006) found that African Americans had a pervasive lack of knowledge about hospice, producing numerous assumptions about hospice services. Misconceptions included that the care would be inadequate, the dying process would be painful and lonely, and that hospice was inaccessible to African Americans because of cost. She also found cultural barriers seemed to play a role, including differences in values regarding planning for end-of-life care, and the importance of family and spiritual or religious practices during the final phases of life. Institutional barriers included mistrust of the healthcare system and the predominantly white providers, lack of knowledge about the scope of services, accessibility, and the cost of hospice programs.

In a study involving focus groups and surveys involving 73 participants who were

Arab Muslim, Arab Christain, Hispanic, black, and white, Duffy, Jackson, Schim, Ronis, & Fowler (2006) found significant differences in end-of-life preferences associated with race/ethnicity and gender. Differences related to how involved family should be in caregiving; where end-of-life care should take place; whether or not "bad news" should be shared with the patient; feelings about assisted suicide, life-sustaining measures, alternative medicine, and advance directives; extent of concern about finances; openness of communication about death; importance of spirituality; extent of medical intervention desired; distrustfulness of doctors and fears of discrimination in medical system; self-determination; and concerns with pain and quality of care.

Theoretical Perspectives

The most widely recognized theories on death and dying focus on the dying individual's experience rather than that of family caregivers or the family unit (Copp, 1998; Corr, 1992; Farber et al., 2003; Glaser & Strauss, 1968; Parry, 2001; Redding, 2000). Some of these theories can be applied to family caregiving and family dynamics or might include reference to family, but were not developed with a focus on the family in mind. A number of theoretical perspectives that directly address family dynamics and caregiving do exist, though, some having direct significance to end-of-life and others more broadly addressing aging. These include *stress-process models* (Kramer & Vitaliano, 1994; Hauser & Kramer, 2004; Kinsella et al., 1998; Lazarus & Folkman, 1984; Lazarus, 1999; Marks, 1998; McCubbin & McCubbin, 1993; Pearlin, Mullan, Semple, & Skaff, 1990; Schulz, Gallagher-Thompson, Haley, & Cazja, 2000; Waldrop,

2006), *resilience* and *strengths perspectives* (Greene, 2002; Greene & Cohen, 2005; Jones, 2007; Jones & Weisenfluh, 2003; Walsh, 2003); *the strength-vulnerability model of family functioning* (Clark et al., 2003; Shields, King, & Wynne, 1995; Shields & Wynne, 1997), *life course role-identity perspective* (Marks, 1998; Moen, Robison, & Fields, 1994*), the ecological perspective* (Bronfenbrenner, 1986; Waldrop, 2006), *the illness intrusiveness model* (Devins et al., 1990), *the family caregiver model* (Nijboer, Triemstra, Tempelaar, Sanderman, & ven den Bos, 1999), and the notion of *reciprocity of suffering* (Sherman, 1998).

Though these theories have relevance to the present study, they are not specific to the construct of family conflict and do not fully capture the perspective employed. An explanatory matrix of family conflict at the end-of-life developed by Kramer et al. (2006) provided the most relevant foundation for this study (see Appendix 1). The only existing theoretical perspective specific to this topic, the matrix portrays family conflict at the end-of-life as a complex, multidimensional phenomenon. As such, the authors suggest that conflict may be influenced by the *family context*, situational *conditions*, and *contributing factors* that result in a number of negative *outcomes* for elders, family members, and professionals. They also highlight *intervening processes* that may mitigate the adverse consequences of family conflict. This perspective acknowledges that conflict can come in a number of forms including that which occurs within the family, between the patient and one or more family members, between the patient and the professional team, and/or between the family and the professional team. Each component of the

matrix will now be discussed to further depict this perspective.

First, conflict is not viewed as a stand-alone phenomenon, but derives meaning only within a *family context*. Historical relationship patterns may influence how family members approach one another and professionals as their relative's health status declines and/or death comes into awareness. The extent and nature of each family member's involvement in care provision may influence their contact with professionals, knowledge of the patient's health status, perceptions of burden, and feelings about how care provision is dispersed among family members. The balance between additional demands outside of the caregiving situation and available resources may play a role in whether or not conflict manifests. Families experience differing degrees of economic resources, psychological or physical health problems, other work and caregiving responsibilities, and family stressors that contribute to the family context.

Second, *conditions* serve to shape actions and/or interactions among family members, underlying the processes of family conflict. The predominant condition fundamental to family conflict is a decline in the patient's health status or functioning brought on by an acute medical crisis and/or elevated frailty that causes death to come into awareness for the patient, family, and or professional team. A co-occurring condition is that of family members "coming out of the woodwork" in response to these changes in health status or a recent awareness of impending death. This phenomenon occurs when family members who had previously had little contact or involvement with the patient "arrive on the scene" and want to be included in decision-making and/or care

provision.

Third, a number of *contributing factors* may accompany the above contextual elements and conditions to fuel conflict. Conflict does not occur just due to family context and/or the above conditions, but in conjunction with them and certain contributing factors. Family members may experience varying levels of difficulty in accepting the terminal nature of the patient's condition, and they may have differing ideas about the patient's health status, care needs, and/or care preferences. Individuals may attempt to assert control, make decisions and engage in actions that thwart the needs and wishes of others. Feelings of anger or distrust may surface as previously uninvolved family members who may not have a good understanding of the patient's condition attempt to participate in decision-making or care planning. As family members attempt to protect one another, communication constraints may inhibit uniform understanding of the patient's health status and needs, as well as the expression of genuine feelings. Efforts to seek resolution of past conflicts may occur as death comes into awareness, and these efforts may result in additional strife rather than peaceful resolution.

Fourth, a number of *consequences* may occur that adversely impact the patient, family, and/or professional team. Care planning and implementation may be restricted or delayed as families argue, struggle with decision-making, and/or focus on other family matters. The patient's wishes and/or quality of care may be jeopardized when communication is disjointed, the patient and/or family are not accepting of the impending death, or the needs of individual family members override those of the patient. Increased

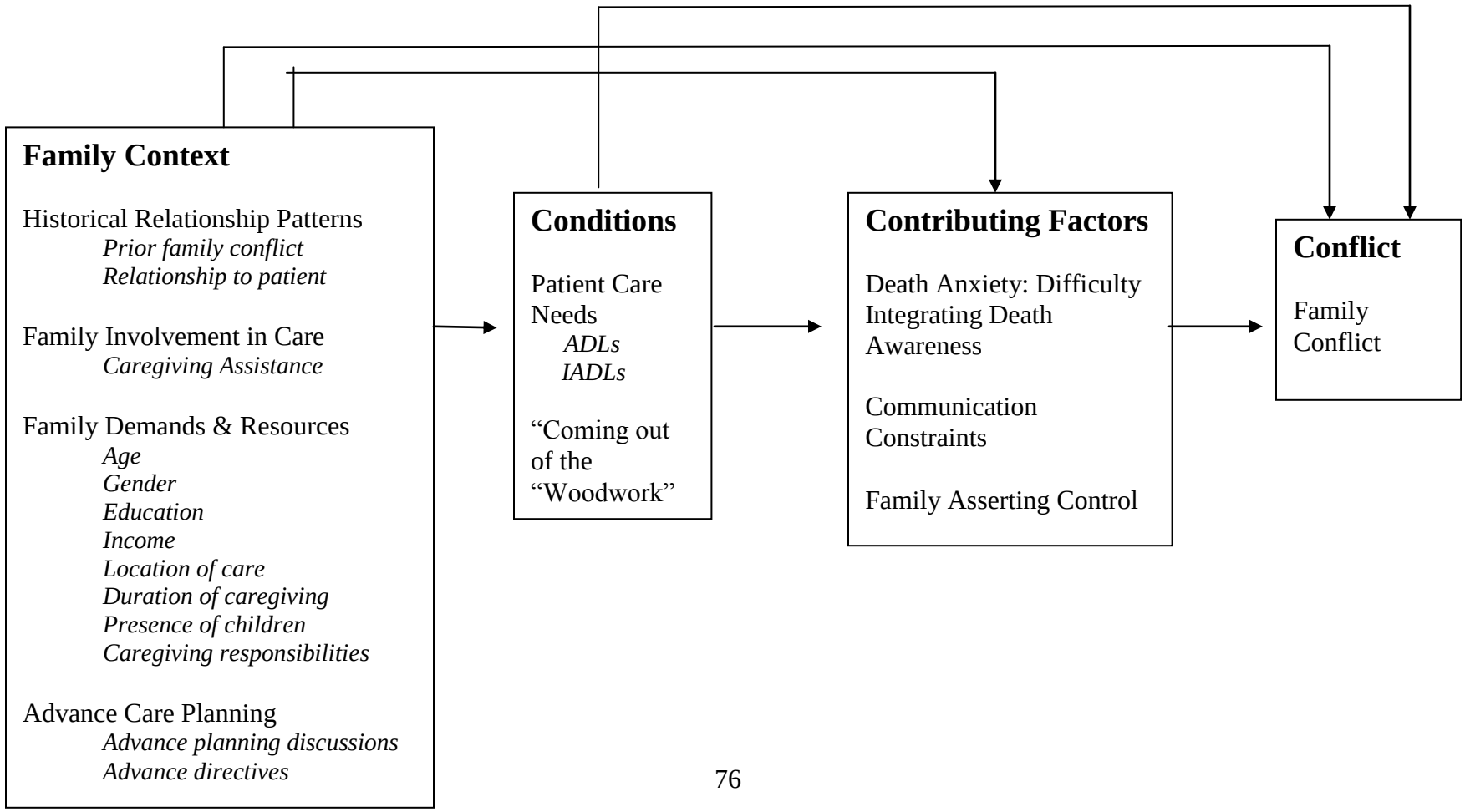
distress or tension for the patient, family, and professional team may result as decisions need to be made, the patient continues to decline, and care planning needs to occur in the context of family conflict.

Fifth, certain *intervening processes* on the part of professionals may attenuate the negative consequences associated with family conflict. Strategies emphasizing individual and/or group and strengths-based family support, education, and counseling may be most effective. Approaches should demonstrate respect for the family unit and work with individual differences in an attempt to build trust.

The current study was guided by this explanatory matrix of family conflict at the end-of-life. Interview and focus group questions were broadly geared towards examining the context, conditions, contributing factors, consequences, and intervening processes associated with family conflict. As such, items already depicted in the explanatory matrix had the potential to surface as did additional themes. Survey questions addressed a number of specific variables depicted in the matrix, as indicated in Figure 1 below. Though the researcher acknowledges that multiple forms of conflict exist, conflict within the family was the focus of this study. Because of the open-ended nature of interview and focus group questions, though, themes of conflict involving outside parties, including hospice had the potential to emerge. This study also attempted to differentiate between enduring and situation-specific conflict, a distinction that was not made in the research conducted by Kramer et al. (2006). Overall, the current study served to determine the extent to which the explanatory matrix of family conflict at the end-of-life could be

supported through inclusion of hospice professionals' and primary caregivers' perspectives. It also investigated elements not included and/or addressed sufficiently in the Kramer et al. (2006) study.

Figure 1. **Explanatory Matrix of Family Conflict at the End-of-Life** *(Variables examined in quantitative portion of this study)*



CHAPTER 3—METHODOLOGY

Project Preparation

To design the study and develop procedures, the researcher consulted with dissertation committee members, hospice social workers and administrators, other researchers with experience conducting similar research, and written guidelines for research in end-of-life care (Addington Hall, 2002; Astedt-Kurki, Paavilainen, & Lehti, 2001; Casarett, 2005; De Raeve, 1994; Hudson, 2003; Janssens & Gordijn, 2000; Kirsch et al., 2004; Kristjanson, Hanson, & Balneaves, 1994; Mount et al., 1995; Waldrop, 2006). Multiple meetings with hospice social workers took place to collaboratively develop a protocol for participant recruitment and survey administration. A number of individuals were asked to review and/or take the survey, including social workers with hospice experience, fellow researchers, and individuals currently serving as caregivers. Revisions were made according to their recommendations. A small grant was obtained through the researcher's employer (UW-Stevens Point) to pay for incentives for research participants, travel, and transcribing. Financial support was also secured through the researcher's department to cover the costs of copying, postage, paper supplies, and phone calls.

Human Subjects Protections

Because of the sensitive subject matter, timing of recruitment, and potential vulnerability of participants associated with this study, special attention was given to developing procedures that would be sensitive to participant life situations, not interfering

with their roles as caregivers or creating additional stressors. As such, the insights and recommendations of hospice social workers were relied heavily upon to determine appropriate procedures that would also maintain the study's integrity. Applications were submitted to and approved by the Institutional Review Boards (IRBs) of the University of Texas, Austin, the University of Wisconsin—Stevens Point, and the University of Wisconsin—Madison (due to the close involvement of Betty Kramer, a committee member who is employed there). While the University of Texas, Austin and the University of Wisconsin—Stevens Point approved the study quickly, The University of Wisconsin—Madison expressed concern that obtaining patient consent was not part of the initial protocol. Though patients would not be directly participating in the research, their caregivers would be sharing personal information about them (i.e. age, diagnoses, needs, family relationships). Therefore, the initial recruitment protocol was revised to include the gathering of patient consent. Ministry Home Care gave formal approval to serve as a research site and did not require an additional IRB process. The principal investigator, co-investigators, and student assistants completed required human subjects training tutorials associated with the above academic institutions.

The potential risks associated with participation were few, and care was taken to minimize their likelihood. First, it was possible that completing the survey and participating in interviews added undue stress to the lives of some caregivers because of the time commitment involved. The researcher deliberately kept the survey short enough to complete in a 15 minute time period, scheduled interviews at times and locations

convenient for the caregiver, and kept the interview time within the parameters initially discussed. Second, though difficult to determine, it is possible that some caregivers experienced adverse emotional reactions to discussing family conflict and/or to completing surveys due to the sensitive nature of the topic, their particular situation, and their stress level at the time of the study. Interview and survey questions were developed with sensitivity, based on researcher knowledge of family dynamics at the end-of-life. The researcher watched for adverse emotional reactions during the interviews and was prepared to offer resources and/or report critical clinical information to hospice staff if needed. In the consent process, caregivers were advised to connect with their hospice social workers if further processing of family issues and/or emotions was needed, and the researcher suggested this as well during interviews as appropriate. Third, it is possible that hospice staff felt threatened by the researcher's involvement in the study and experienced difficulty in processing their own practice experiences. The researcher attempted to minimize this by building strong, productive relationships with the staff, including them in study decisions, and offering validation and support for their experiences.

Ministry Home Care and its consumers potentially benefited in a number of ways by participating in this study. First, through learning the results of the study, the hospice program received insight into the perspectives of primary caregivers, variables associated with conflict, and ideas as to how to better help patients and families. Hospice programs have a mandate to address family needs, and the findings of this study helped inform

them to better serve the needs of the family. Second, participating caregivers received increased attention through researcher visits. Though the researcher did not provide hospice care or counseling services, her visits allowed family members to discuss their situations. The ability to process their situations with a neutral party was likely therapeutic for some caregivers. Third, primary caregivers received a small incentive in the form of a gift certificate for participating in the study.

Study Setting

One of 61 hospices licensed to operate in Wisconsin (Wisconsin Department of Health and Family Services, 2005) Ministry Home Care has locations throughout northern, central, and eastern Wisconsin with offices in Arbor Vitae, Marshfield, Neenah, Rhinelander, Stevens Point, Sturgeon Bay, Wausau, and Wisconsin Rapids (Ministry Health Care, 2006). Ministry Home Care is a non-profit organization, which is typical in Wisconsin where nonprofit organizations serve approximately 77% of all hospice patients (Wisconsin Department of Health and Family Services, 2005). Ministry Home Care is a member of Ministry Health Care Network, a Catholic-based health care delivery network of aligned hospitals, clinics, long-term care facilities, home care agencies, dialysis centers, and other programs and services in Wisconsin and Minnesota. Ministry Home Care provides both hospice and home health care services to patients and their families in 30 counties across Wisconsin and is Medicare and Medicaid certified. A relatively new organization, it was formed in 1998 when a number of existing home health and hospice programs came together to form one organization. Two Ministry Home Care sites agreed

to participate in this study, Marshfield and Stevens Point.

Ministry Home Care in Marshfield serves portions of Wood, Clark, Marathon, and Adams Counties. In addition to traditional hospice services, it also operates a licensed residential hospice facility (House of the Dove). In 2005, this program served 343 patients and had an average daily census of 51. Patients age 65 and older comprised approximately 90% of the patients served, with approximately 44% being male and 56% being female. Diagnoses of patients were distributed as follows: cancer (47%), cardiovascular disease (14%), pulmonary disease (10%), renal failure (5%), Alzheimer's disease (6%), ALS (2%), and other (17%). The vast majority of discharges from this program were due to death of the patient (93%) and 49% of the deaths took place in a private residence. Payment sources were as follows: Medicare (76%), Medicaid (3%), Medicare/Medicaid (14%), private (6%), and other (1%). Routine home care was by far the biggest category of service provided (99%). The majority of patients enrolled stayed in the program 1 to 7 days (24%), with other enrollment times as follows: 8 to 14 days (14%), 15 to 29 days (20%), 30 to 59 days (15%), 60-89 days (7%), 90-179 days (11%), 180 days to 1 year (7%), and 1 year or more (2%) (Wisconsin Department of Health and Family Services, 2006).

Ministry Home Care in Stevens Point provides hospice services in portions of Portage, Waushara, and Marathon counties. Ministry Home Care in Stevens Point is one of two hospice providers situated in Portage and Marathon Counties and the only provider in Waushara County. In 2005, this program served 183 patients and had an

average daily census of 32. Patients age 65 or older comprised 85.5% of the total patients served, with 41% being male and 59% being female. Diagnoses of patients served were distributed as follows: cancer (46.4%), cardiovascular disease (16.4%), pulmonary disease (6%), renal failure (1.6%), Alzheimer's disease (12.6%), AIDS (1.1%), ALS (1.1%), and other (14.8%). The vast majority of discharges from this program were due to death of the patient (92.3%) and 64.3 % of the deaths occurred in a private residence. Primary payment sources were Medicare (84.8%), Medicaid (1.9%), managed care (1.9%), private insurance (8.2 %), and other (3.2%). Routine home care comprised 98.7 % of the total care provided in 2005. The majority of patients enrolled stayed in the program 1 to 7 days (31.4%), with other enrollment times as follows: 8 to 14 days (11.3%), 15 to 29 days (15.7%), 30 to 59 days (12.6%), 60 to 89 days (4.4%), 90 to 179 days (13.2%), 180 days to 1 year (5.7%), and 1 year or more (5.7%) (Wisconsin Department of Health and Family Services, 2006).

These figures suggest that Ministry Home Care is fairly representative of hospice care state and nationwide with the exceptions being that it serves a slightly older demographic and has slightly fewer very short lengths of stay. Both sites serve a relatively higher number of patients and families than other small town/rural hospice programs due to their large service areas and affiliation with a highly respected health care organization. Both sites have been established in their communities for quite some time and have good reputations for providing quality hospice care. These sites have a relatively large number of social workers on staff, and unlike many hospice programs,

social workers have an active role in facilitating the admission process. This role was important in terms of recruiting caregivers for this study in that social workers had early access to families and were already completing administrative work with them.

Design

This study aimed to explore and describe the phenomenon of family conflict, allowing for in-depth understanding of the experiences of those involved and taking into account context and setting. Qualitative and quantitative methods were employed in an attempt to understand family conflict at the end-of-life from the perspective of both hospice staff and family caregivers. A concurrent triangulation mixed methods design was used utilized in which qualitative and quantitative data were collected and analyzed at the same time, priority was equal and given to both forms, data analysis was separate, and integration occurred at the interpretation stage (Hanson, Plano Clark, Petska, Creswell, & Creswell, 2005). Data triangulation occurred, which refers to the gathering of data through several sampling strategies, so that slices of data at different times and social situations, involving a variety of people are gathered (Denzin, 1970). In this case, hospice professionals from multiple disciplines were involved, as were hospice family caregivers. To the researcher's knowledge, this is the first study focused on family conflict at the end-of-life from the perspectives of hospice caregivers and professionals. Method triangulation also occurred, which refers to the use of more than one method for gathering data (Denzin, 1970). In this case, qualitatively oriented discipline-specific focus group sessions with hospice professionals, qualitatively oriented interviews with

hospice family caregivers, and quantitatively oriented surveys of hospice family caregivers were used.

The in-depth interviews and focus groups aimed to generate theory regarding family conflict from the perspectives of hospice primary caregivers and hospice staff. According to Marshall & Rossman (1994), qualitative methods are ideally suited for research that is "exploratory or descriptive, that assumes the value of context and setting, and that searches for a deeper understanding of the participants' lived experiences of the phenomenon" (p. 38). The surveys were utilized to examine the correlates and predictors of family conflict at the end-of-life. Mixed methods approaches allow researchers to better understand research problems by converging numeric trends from quantitative data and specific details from qualitative data, enrich the understanding of an experience through confirmation of conclusions or extension of knowledge, and enhance study validity (Bazeley, 2004; Golafshani, 2003; Hanson et al., 2005)

Sample, Recruitment, and Inclusion Criteria

The sample of hospice professionals consisted of all direct care staff employed by Ministry Home Care in Marshfield and Stevens Point during the time of the study. At the time of the study, the two sites collectively employed 15 nurses, 9 nursing aides, 2 bereavement counselors, 9 social workers, 3 chaplains, 2 volunteer coordinators, and 2 administrators. Beyond preliminary planning meetings with hospice administrators and social workers, the hospice staff was oriented to the research project in April of 2007. The researcher attended a staff meeting to engage in introductions, explain the overall

study purpose, provide a brief overview of the study, and address questions and concerns. In accordance with Kirsch et al.'s (2004) recommendations for working with hospice staff, the researcher briefly discussed ethical issues and the IRB process to address potential concerns about harming participants and about confidentiality. The researcher also provided each staff member with a copy of the survey and interview schedule to be used with caregivers.

At this orientation meeting, the researcher informed staff of the opportunity to participate in focus groups and briefly discussed the purpose and format of the groups. The researcher discussed the risks and benefits associated with participation and also noted that food and beverages would be provided during the meetings. The researcher gave each staff member a business card and encouraged them to contact her with additional questions and concerns. In Marshfield, nursing specific focus groups were scheduled by use of a sign-up sheet posted in the hospice office. All other focus groups were arranged through a hospice supervisor, who encouraged participation and scheduled meeting rooms and times. Prior to scheduled focus group meeting times, the researcher called and/or e-mailed to confirm the session and encourage participation. The consent process was completed at the beginning of each focus group meeting.

The sample of primary caregivers consisted of all primary caregivers of hospice patients admitted from April 30, 2007 to June 20, 2007; October 1, 2007 to January 1, 2008; and March 1, 2008 to March 15, 2009. Unless screened out by the admitting hospice social worker or not eligible due to patient refusal, all caregivers were invited to

participate in the survey component of the study. Primary caregivers were recruited by social workers during the hospice admission process (see Appendix 2 for recruitment protocol). Recruitment occurred at every admission (home, group home, hospice house, inpatient, nursing home), unless the patient was perceived as "actively dying" or the social worker believed that introducing the study at the time of admission would cause undue distress to the caregiver. For example, if the caregiver was experiencing anxiety attacks or was assessed as severely depressed at the time of admission, the social worker had the option to decide that the timing was not suitable for introducing the survey. In these situations, the social worker documented the specific reason for this clinical judgment and offered the survey at the following visit when possible. Social workers were reminded that family caregivers were the best judge as to whether or not they were capable and willing to complete the brief survey and/or participate in a future interview. The consent form fully described their rights and responsibilities allowing them to make this decision for themselves. The importance of all eligible family caregivers being provided the opportunity to participate was emphasized to the social workers, explaining that if only the most highly functioning family members were offered the survey, it would compromise the potential value of the knowledge gained.

The admitting social worker verbally explained to the patient and caregiver (or caregiver only in the case of patient incapacity) that there is a social work researcher who would like to learn more about the challenges faced by families in hospice. The social worker stated that the researcher is asking all caregivers involved with hospice to

complete a short survey, and that a small number of primary caregivers will also be invited to participate in interviews. The social worker mentioned that participation in the research is completely voluntary and confidential and will not affect their hospice care in any way. The social worker acknowledged that the caregiver may be very busy with caregiving and other responsibilities, but that the research would hopefully help hospice programs to better serve families in the future. The social worker mentioned that completing the survey would take about 15-20 minutes and that a $5 gas card would be awarded for completed surveys.

Upon gaining patient consent, the social worker completed the consent process with the caregiver and then presented the caregiver with a folder that included an introductory letter, survey, and return envelope. The introductory letter (Appendix 3) briefly explained the survey process, provided contact information for the researcher, and thanked them for agreeing to participate. It also described incentives available for completing the survey as well as for interview participation. The patient and caregiver consent forms were designed in keeping with the University of Texas consent protocol and additionally asked if the caregiver was willing to be contacted for survey follow up and/or a follow up interview. If agreeable to follow up, the caregiver was asked to provide contact information. The patient and caregiver consent forms were then immediately mailed back to the researcher by the admitting social worker. Upon receiving the consent forms, the researcher made a follow up call to each primary caregiver who agreed to survey follow up to thank them for agreeing to participate,

encourage them to complete the survey, and address any questions they might have (see Appendix 4 for follow up script).

When each completed survey was received, the principal investigator mailed a thank you card and $5 gas card to the caregiver. She then reviewed the survey to screen for inclusion in the interview component of the study. Caregivers who agreed to interview follow up and whose surveys 1) reflected family conflict as determined by responses to the family conflict questions in the survey (i.e. at least "a little" conflict on more than one item of the family conflict scale), and 2) indicated that the respondent was an immediate family member of the patient, were contacted via telephone by the researcher. Upon calling, the researcher determined whether the patient was still in hospice, the caregiver was willing to meet in person, and that the timing for participation was still appropriate (as a matter of ethics and practicality, this component of the study did not include family members of patients who were facing an imminent death). Interview appointments were scheduled at the caregiver's convenience in their location of choice. Confirmation calls were made the day prior to or of the interview. The consent process was completed upon arrival to the interview. Caregivers who completed an interview were given a $10 gas card and were sent a thank you note afterwards.

Data Collection

The researcher's background as a social worker served her well during data collection. She has approximately six years of direct practice social work experience, five of which were in health care, and three of which were specifically in hospice. She

has significant experience working with patients and families involved in end-of-life care as well as hospice professionals. During her time with hospice, she worked for Ministry Home Care in Stevens Point, so was familiar with this organization's policies, procedures, and structure. She had not been employed by Ministry Home Care for approximately 6 years, though, so was far enough removed as to not create a conflict of interest or bias study results through personal relationships. Beyond her direct practice experience, the researcher has conducted research and professional presentations on end-of-life issues and has served as a member of a local Community Coalition for End-of-Life Care. She has taught courses on medical social work, death and dying, interviewing, and group work.

Data collection occurred in three ways: completion of caregiver surveys, in-depth caregiver interviews, and hospice staff focus groups. Strategies used for enhancing rigor in data collection were 1) triangulation (the data was be obtained from multiple sources representing different stake holders' views) 2) collection of caregiver data while their loved one was actually enrolled in the hospice program (caregivers did not have to rely on recall to answer the questions, as they were currently living the situation), and 3) careful training and consultation with hospice social workers related to the recruitment process.

Primary Caregiver Survey

The self-administered survey was used to collect quantitative data in order to examine the correlates and predictors of family conflict at the end-of-life. It was

hypothesized that family conflict is fueled by factors associated with the family context, conditions underlying the processes of family conflict, and additional contributing factors associated with the end-of-life situation itself. The survey was also utilized to determine the extent to which families enter hospice with prior conflict and the extent to which conflict follows a terminal diagnosis. A preliminary study suggests that some forms of conflict may be enduring and some may be situation specific (Kramer et al., 2006). Understanding this distinction may be important when considering appropriate professional interventions and identifying forms of conflict amenable to change.

Combining a number of brief scales and items developed by the researcher, the survey (Appendix 5) was designed using standard recommendations for question form and wording, topic order, question order, response choices, and layout (Fink & Kosecoff, 1998; Rubin & Babbie, 2001; Weisberg, Krosnick, & Bowen, 1996). With a total of 100 questions, the survey took between 15 and 25 minutes to complete (estimating 10 seconds per question).

Primary Caregiver Interviews

In depth interviews were used to more deeply explore primary caregivers' experiences with family conflict as the conflict was occurring. For each participating caregiver, a semi-structured interview (Appendix 6) took place while their loved one was still in hospice. Questions focused on relationships among involved family members, sources and history of conflict, the nature of existing conflict, perceived causes and consequences of conflict, family attempts to resolve conflict, hospice involvement in

dealing with conflict, perceived solutions to conflict, and family views of the patient's condition. Open-ended questions were used to allow caregivers to share their experiences in their own way, followed by probing questions as needed to encourage greater depth of discussion. Participants were encouraged to proceed at a pace and in a direction that was comfortable for them. Interviews lasted between 45 minutes and 2 hours and were audio recorded. The researcher took minimal notes during the interview in order to maintain focus on the caregiver. Eleven interviews took place in caregiver homes, one in a skilled nursing facility, one in a community based residential facility, one at a local library, and one at the caregiver's place of employment.

Focus Groups

Discipline-specific focus groups were utilized to gain insight on professional perceptions and experiences with family conflict at the end-of-life. Open ended and probing questions focused on definitions and types of conflict, examples of conflict, significance of conflict, causes and contributing factors, consequences, strategies for preventing and addressing conflict, and challenges in working with families who experience conflict. Guidelines for focus group protocols were followed (Krueger, 1994; Edmunds, 1999). As such, the focus group discussion guide (Appendix 7) included a greeting, explanation of purpose, and discussion of ground rules. It also included opening, introductory, transition, key, and ending questions. In addition to the group discussion, fourteen staff members were asked to complete the following sentences in writing: "Family conflict is…" and "I have seen family members disagree about…"

Focus groups were recorded and transcribed verbatim and written responses were typed verbatim.

Response Rates

Survey. The response rate over the first two months of the survey component of the study was incredibly low (17% for Stevens Point and 22% for Marshfield), likely due to the recruitment methods employed. At that time, participants were being recruited through the social work staff upon admission. The admissions coordinator would introduce the study over the phone prior to admission visit when able. Social work staff had authority to decide if the timing was not good to introduce the study due to the patient actively dying and/or the family being too overwhelmed. Otherwise, the social workers simply introduced the study and, if the patient agreed and the caregiver expressed interest, they left the survey packet, including caregiver consent form, for the caregiver to review, complete, and return. They obtained patient signatures on the consent form, but did not gain the written consent of caregivers. It was discovered that one of the lead admission social workers was often forgetting to offer the survey, on a couple of occasions did not give it due to patient incapacity, and on a couple of occasions did not give it because family was not present at the time of admission (all of which were not congruent with the agreed upon protocol). There was also some concern that social workers may be inappropriately screening potential candidates out.

Therefore, recruitment was temporarily put on hold so that the researcher could meet with social work staff to revise the recruitment protocol in hopes of enhancing

response rate. A meeting was held with social work staff at each site to discuss how social workers were approaching patients and caregivers about the survey, how patients and caregivers responded when approached, what the social workers perceived as barriers to survey completion by caregivers, and social workers' ideas for improving response rate. The researcher came to these meetings prepared with ideas for improving response rate as well, many of which were derived from Dillman's (1978) Total Design Method.

After meeting with social workers from both study sites, a new protocol was devised, approved by all IRBs, and used throughout the remainder of the study. Instead of admitting social workers only obtaining written patient consent and returning the form back to the researcher, they would also obtain written caregiver consent and return it to the researcher at the same time. The hope was that this would result in caregivers being more committed to completing the survey (because they had signed something). A decision was also made to revise the caregiver consent form to include an area in which the caregiver could indicate willingness for follow up contact regarding the survey and for a follow up interview. Once the patient and caregiver consents were received by the researcher, she would then follow up with a phone call to thank the caregiver for agreeing to participate, ask if they had questions and/or needed assistance with the survey, and encourage completion. It was agreed that the researcher would only follow up one time, as to not be intrusive. The appearance of the survey packets was also improved as part of this revised protocol and blue folders were used instead of white, as social workers indicated that the survey packets were at risk for getting "lost in the shuffle" with all of

the other hospice paperwork processed at admission.

Of the approximately 800 patients admitted to the program during the remaining survey recruitment period, a total of 235 patients and their caregivers collaboratively consented to participation in the survey. Those who did not consent included families in which the social worker made a clinical judgment to not offer the survey due to severe distress on the part of the patient and/or family, the patient being in a state of actively dying during the admission process, and/or an extremely chaotic admission process that deemed discussion of the survey inappropriate. It also included patients and family members who, upon being offered the survey, declined participation citing a number of reasons such as just not being interested, having too many other things to focus on, and disliking surveys. So, of the 235 survey packets administered by social work staff, 136 were completed (58%). The 136 surveys completed during this time period combined with the 25 completed during the early months of the study resulted in a total of 161 surveys completed. Given the target population of the study and the timing of recruitment in the context of their end-of-life experience, this response rate is respectable.

There are a number of reasons that people who originally agreed to participate may not have actually completed the survey. A sense for this was gained through discussions with the hospice social workers and phone conversations with the caregivers during follow up. The social workers indicated right from the start of the study that patients and family members are often overwhelmed at the time of admission and that completing a survey may not be a priority for them. They receive a lot of information

and go through a lot of paperwork and even if interested in completing a survey, may not do so due to information overload. When the researcher made follow up calls to caregivers to encourage participation and offer assistance with survey completion, some seemed unaware of the survey even though it had been presented to them in the last week, and many reported being extremely busy, under pressure, and stressed. Because of the quantity of hospice and other paperwork they were already exposed to, many had to be directed as to what the survey looked like and where it might be and many admitted having forgotten about it. The follow up calls likely helped in these circumstances to improve response rate. Another reason that surveys were not completed was that follow up calls revealed that the patient had died. In these instances, condolences were offered and the caregiver was not advised to complete the survey as to not burden them during an already difficult time and also because the survey was designed to be completed while the patient was still living. There is no way to accurately calculate how many patients died before their caregiver was able to complete the survey, as the researcher did not directly speak to all caregivers on follow up (many voice mails were left). Referring back to the length of stay data presented above, though, we know that the majority of patients admitted into Ministry Home Care, Hospice remain in the program from 1 to 7 days.

Focus Groups. Out of the 42 staff eligible to participate in the study, 37 took part in one or more of the focus group sessions (86%). Those not participating cited scheduling problems as their reason for refusal (either they were not working at the time of the session and did not want to come in on their day off or they had to attend to

patient/family needs).

In-Depth Interviews. Of the 73 primary caregivers who met inclusion criteria for the interview component over the course of the study, a total of 15 were interviewed. In some instances, caregivers indicated on their consent forms that they did not wish to participate in a follow up interview. Some became ineligible due to patient death, and others were no longer interested or able at the time of follow up. When time constraints prevented the researcher from interviewing all eligible and willing caregivers who had completed surveys, those evidencing more substantial conflict were interviewed until the target sample size was obtained.

Data Collection Challenges

A number of challenges surfaced during the data collection phase of this study. The researcher attempted to address all of these challenges through deliberate efforts to build relationships with the hospice staff and to convey respect for their experiences, practice wisdom, and time. The researcher helped staff to understand the purpose and value of the study and reassured them that their performance was not being evaluated. In accordance with Kirsch et al.'s (2004) recommendation, the researcher worked with staff and administrators to examine ways in which the study could be conducted in the least intrusive way for staff. The researcher also helped the social workers understand the human subject protections in place and the need to give caregivers a chance to participate in this valuable research. Multiple focus groups were scheduled to reduce the likelihood of interfering with staff work.

First, assisting with research altered the daily routine of the hospice social workers who presented the study to caregivers and patients. They had to add the study protocol to their existing list of things to discuss upon admission and field patient and caregiver questions. The social workers expressed concern over adding one more thing to their long list of admission tasks, and feared that having to present the study would detract from other important work they needed to do with the patient and the family. Some social workers expressed feeling awkward about discussing the survey with families when there was other important family focused business to attend to. Reflecting this challenge, research on the participation of hospices in research studies revealed that only 19% of hospices reported participation in the previous year, with time demands and ethical concerns among the reasons cited for lack of participation (Casarett, Karlawish, & Hirschman, 2002). Out of respect for these concerns, efforts were made to minimize the time spent by social workers on this study. When attempting to address the above noted response rate concern, the social workers stressed the need to keep their role minimal, and some ideas for improving response rate were not acceptable to them. For example, the approach of asking the caregiver to complete the survey while the social worker was in the home was discussed, as was the idea of the social workers being involved in a follow up process.

Second, because the aim of this study was to learn the perspectives of caregivers while they were experiencing the dying process of a family member, the stress level and emotional state of participants needed to be considered. The research protocol had to be

developed with the utmost sensitivity for caregiver situations and the researcher had to be prepared to respond to caregiver emotions in person and over the phone. As indicated above it is highly likely that caregiver emotions and stress contributed to lower than ideal response rates. Further, in several instances, incomplete surveys were returned, some in which entire pages had been skipped. In these instances, the missing parts of the survey were returned to the caregiver with a polite request to consider completion.

Third, time was needed for hospice staff to participate in focus groups and meetings regarding the project. Scheduling times that worked for everyone and did not interfere with their work was challenging. Because participants were "on the job" while participating in focus groups and meetings, pagers went off frequently and some participants had to leave to respond to a patient or family need. Organizational changes (computerization, staffing) and the medical leaves of two key players occurred within the agency during the study and placed additional stress upon staff, who struggled to manage their workloads within their hours scheduled. Morale was low at times due to workplace conflict and employee stress. Ultimately, nursing staff would only allow ½ hour to 45 minutes for focus groups, which left little time for in-depth discussion. It was difficult to get all of the social workers together in the same room to meet about the survey protocol, as the study involved social workers at four different branch offices with at least 30 miles between them. This left room for miscommunication, as supervisors and social workers had to pass along information to those who were not able to be present. Efforts were made to include social workers via conference calls, though even then, patient and family

needs took precedence over discussing the study. E-mail and voice mail were used to encourage social workers to express concerns and ask questions throughout the life of the study, and this mode of communication seemed to work quite well.

Fourth, during focus groups the researcher got the sense that participants had a hard time focusing on the issue of family conflict specifically and would start to talk about challenging or "difficult" families versus families with conflict. "Difficult" patients and families are thought to be common in many medical settings (Hahn et al., 1996; Lichtenthal & Kissane, 2008), but are not equivalent to families who are in conflict in all cases. Frequently reminding them of the specific topic at hand became important to eliciting relevant responses.

Data Analysis

Quantitative Analysis

Quantitative analysis included descriptive (e.g., to report frequency of conflict among hospice families), and inferential statistics (e.g., to examine correlates and predictors of conflict). With 161 surveys received, there were a maximum of 161 usable sets of responses, with some dropping out of a specific model estimation due to missing data. Minimum sample size guidelines were met for the regression technique utilized, following the recommendation of not more than 1 variable for each 10 in the sample or a sample of at least 50 + 8m (where m = the number of factors) (Abu-Bader, 2005; Allison, 1999; Kline, 2005; Tabachnick & Fidell, 2001). A colleague with expertise in statistical analyses assisted with designing, carrying out, and interpreting the analysis.

Surveys were coded and entered into SPSS. Scales were constructed and tested for reliability (results are reported below). Missing data were reviewed and a number of errors in coding were corrected. Several strategies for handling remaining missing data were then utilized. In a few instances, missing responses were able to be accurately inferred due to notes made by respondents in the margins of the survey or by reviewing other survey questions. For example, one respondent left the question regarding location of care blank, but had previously written in the margins that the nursing home took care of all patient cares. In this instance, nursing home was inferred as the location of care. Mean substitution (Downey & King, 1998) was used for the family conflict and communication constraints scales in which 50% or more of the data was available. In situations in which half of the items are present, this method has been found to be the optimal technique for imputing missing data (Hawthorne & Elliott, 2005). This applied to seven respondents on the communication constraints scale, two of which completed two of the four available items and five of which completed three. This applied to six respondents on the family conflict scale, five of which were missing just one of the eight items and one of which was missing two. For remaining missing data, listwise deletion was utilized, meaning that the analyses ran only on observations that had complete data for all of the variables included. When any of the variables were missing, the entire observation was omitted from the analysis. This method is acceptable if only a few cases have missing data and they seem to be a random subsample of the whole sample (Tabachnick & Fidell, 2001). A t-test was conducted to examine whether those in the

analytic sample for the regression analysis were different from the remainder on the outcome of interest, family conflict, with the result indicating no significant difference (t=.86, p=.39).

The quantitative analysis of survey responses involved standard univariate analysis of major variables in the survey (descriptive statistics and graphs, etc.) followed by a series of bivariate and mutlivariate analyses. First, zero-order correlation coefficients were used to check for presence and size of statistical relationship between each of the context variables (i.e. historical relationship patterns, family involvement, family demands and resources, advance care planning) and the condition variables (i.e. "coming out of the woodwork" and patient clinical needs) on the outcome of interest, family conflict. Second, a regression analysis was conducted, controlling for context and condition variables to examine the effect of certain contributing factors (i.e. death anxiety, communication constraints, family asserting control) on family conflict.

Measures

A number of measures were embedded in the survey, some of which were developed and established through previous research and some of which were developed specifically for this study. These measures will now be described, categorized in relation to their placement in the conceptual model of family conflict at the end-of-life.

Family Conflict at the End-of-Life

In attempting to locate an appropriate family conflict measure for use in this study, scales related to family environment, family functioning, family adaptability,

family cohesion, family stress, family change, family coping, and family well-being were obtained and reviewed. Several instruments contained specific items addressing conflict, but did not measure conflict overall. Scales designed to measure conflict with respect to caregiving for persons with Alzheimer's disease (Semple, 1992) and stroke (Clarke et al., 2003) exist, as do scales measuring interparental conflict (Kline, Wood, & Moore), conflict in Asian American families (Lee, Kim, & Ngo, 2000), and general conflict in the family environment (Moos & Moos, 1994).

Given the absence of available measures to specifically examine family conflict at the end-of-life, a measure recently developed by Kramer was adapted for use in this study. Kramer generated items for this measure from findings from a qualitative study of family conflict (see Kramer et al., 2006), a review of the literature, prior clinical experience, and consultation with clinicians with expertise working with families in palliative care. Respondents were asked to use a 5 point scale (1=not at all to 5=very much) to answer the following eight questions anchored in the end-of-life experience: "As you think about your family since your relative was diagnosed with a life-threatening illness, how much do any family members: Disagree or argue with one another about health care decisions for your relative?; Disagree or argue with one another about your relative's illness or physical condition?; Disagree or argue with a family member about the way they were treating your relative (e.g., not visiting)?; Disagree or argue about certain family members not pulling their weight to help provide care for your relative?; Insult or yell at one another?; Disagree or argue about what is meant by "a good death"?;

Disagree or argue about how money is being spent or being used?; Disagree or argue about where your relative should live out his/her remaining days? Higher scores on this measure indicated higher levels of family conflict at the end-of-life. Cronbach's alpha for this 8-item scale was .89; item to total correlations ranged from .51 to .76. The family conflict scale was extremely skewed and a logarithm transformation was necessary to improve its distribution (Tabachnick & Fiedell, 2001). An assumption of regression is that the dependent variable is normally distributed (Allison, 1999, Tabachnick & Fidell, 2001).

As expected, the family conflict at the end-of-life measure correlated highly (r = -.61, $p \leq .001$) with the family functioning measure included in the survey, supporting the construct validity of the family conflict measure. The family functioning measure consisted of a shortened self-report version of the Family Assessment Device (Miller, Epstein, Bishop, & Keitner, 1985), which has been used in numerous studies and is regarded as one of the most researched family assessment tools available (Ridenour, Daley, & Reich, 1999). An adapted version of the general functioning subscale was used due to its ability to assess the overall health/pathology of the family. The scale consisted of six items addressing aspects of family functioning. Using a 5 point scale (1 = strongly agree to 5 = strongly disagree) respondents were asked to indicate the extent to which they agree or disagree with the following statements: "planning activities is difficult because we misunderstand each other," "in times of crisis we can turn to each other for support," "individuals are accepted for what they are," "there are lots of bad feelings in

the family," "we are able to make decisions about how to problem solve," and "we don't get along well together." Both the internal reliability and validity of the Family Assessment Device have been demonstrated in prior research with Cronbach alphas on the subscales ranging from .74 to .92 (Epstein, Baldwin, & Bishop, 1983; Miller et al., 1985). The reliability and validity of the 12-item general functioning subscale has been examined with results indicating good reliability and validity (Byles, Byrne, Boyle, & Offord, 1988). A reliability check of this 6-item scale utilized revealed a Cronbach's alpha of .83, with item to total correlations ranging from .52 to .69.

Family Context Variables

Caregiver Age

Respondents were asked to indicate their own actual age in years. Responses were coded as specified, so the higher the number of this variable, the older the caregiver (respondent).

Caregiver Gender

Respondents were asked to indicate their own gender. This was coded as a dichotomous variable (0=male, 1=female).

Caregiver Education

Though the survey allowed six response options indicating various levels of caregiver education, during analysis this variable was dichotomized (0=less then high school, 1=more than high school) to get a sense for potential differences between those who had not completed high school versus those who had completed high school and

beyond.

Caregiver Income

Though the survey included seven response options for caregiver income, during analysis the variable was dichotomized (0=$20,000 or less, 1=higher than $20,000) to try to capture potential differences between those who are very poor versus those with middle to high incomes.

Location of Care

Respondents were asked to respond to "where is your family member living right now?" with response options of "in their own home," "in a family member's home," "in assisted living or group home," "in House of the Dove," "in a nursing home," or "other." During analyses, these categories were collapsed to two options, in own/family member home (coded as 0) and other settings (coded as 1) to capture potential differences between those being cared for in a personal residence versus those being cared for in a professionally operated setting.

Relationship to Patient

Respondents were asked to indicate their relationship to the patient, with response options of spouse, parent, child, sibling, significant other but not married, and other. Because so many respondents indicated "other," and wrote in a specific relationship, this category was reviewed and five distinct categories were formed for analysis (0=spouse/significant other/life partner, 1= sister/brother/sister-in-law/brother-in-law, 2=daughter/son/daughter-in-law/son-in-law, 3=parent of child, 4=other family and

family-like friends).

Duration of Caregiving

Respondents were asked to indicate how long they have been helping their family member, with responses coded in months of caregiving. Thus, the higher the number on this measure, the longer the length of caregiving.

Prior Family Conflict

No other instruments exist to measure prior family conflict. As such, Kramer recently developed a 2-item scale for prior family conflict based on findings from a qualitative study (see Kramer et al., 2006), a review of the literature, prior clinical experience, and consultation with clinicians with expertise working with families in palliative care. Respondents were asked to think about their family before their relative was diagnosed with a life-threatening illness and use a 5 point scale (1=not at all to 5=very much) to indicate the extent to which family members "have serious arguments with one another" and "insult or yell at one another." Higher scores on this measure indicated higher levels of prior family conflict. A Cronbach's Alpha reliability check on this two-item scale came in at .83.

Caregiving Assistance

Family involvement was measured through one survey question, which asked the respondent to indicate how many additional family members provide help to the patient. Though respondents indicated the actual number of family members providing help to the patient, a dichotomous variable was ultimately developed for analysis (0=no help from

family, 1=receives help from family). This question allowed for examination of family involvement as it relates to family conflict in a concrete sense.

Caregiving Responsibilities

The extent to which respondents had additional caregiving responsibilities was measured through one item that asked, "Are you currently providing care for any other family members or friends because of an illness, disability, or advanced age?" with a yes/no response option (0 = no, 1 = yes). The literature suggests that many caregivers assume multiple caregiving roles simultaneously, possibly contributing to conflict and other adverse outcomes.

Presence of Children

Presence of children in the caregiver's home was measured through one item that asked, "How many children under the age of 18 are living in your home?" Though respondents were asked to indicate the actual number of children, two groups were formed for analysis, caregivers with children under 18 (coded as 1) and caregivers with no children under 18 (coded as 0). The literature suggests that other life roles may complicate the caregiving experience, possibly contributing to conflict and other adverse outcomes.

Advance Planning

Though four survey questions addressed advance planning, one was selected for use during analysis. Respondents were given a 5 point scale (1= strongly agree to 5 = strongly disagree) to indicate their level of agreement to "my family discussed our family

member's wishes for care before he/she became ill." The item was then reverse coded for direction so that higher scores on this measure indicated higher levels of advance planning. As indicated in the above literature review, it is thought that advance planning may reduce family conflict.

Advance Directives

Respondents were asked to indicate, in two separate questions, whether the patient had completed a power of attorney for health care and whether they completed a living will. They were given the response options of "before he/she became ill," "after he/she became ill," "not at all," and "don't know/can't say." Dichotomous variables were constructed for both power of attorney and living will during analysis, in which "before he/she became ill" and "after she/he became ill" became one category (1=yes) and "not at all" and "don't know/can't say comprised the other (0=no).

Condition Variables

Activities of Daily Living (ADLs)

From a list of daily living activities based on Katz, Down, Cash, & Grotz (1970) (i.e. bathing, dressing, toileting, transferring, incontinence, feeding) respondents were asked to indicate tasks the patient needed assistance with by checking the respective box (0=no, 1=yes). Scores for the total list were then tallied so that higher scores on this measure indicated higher ADL needs. Research has suggested, and clinical practice indicates, that patient needs correlate with caregiver stress, which may have a role in family conflict. Cronbach's alpha for this 6-item scale was .89, with item to total

correlations ranging from .60 to .86.

Instrumental Activities of Daily Living (IADLs)

From a list of instrumental activities of daily living based on Lawton & Brody (1969) (i.e. shopping, food preparation, housekeeping, laundry, transportation, medication, finances) responsents were asked to indicate tasks the patient needed assistance with by checking the respective box (0=no, 1=yes). Scores for the total list were then tallied so that higher scores on this measure indicated higher IADL needs. Cronbach's alpha for this 7-item scale was .93, with item to total correlations ranging from .64 to .85.

"Coming out of the Woodwork"

A single question addressed the "coming out of the work phenomenon" illustrated by Kramer et al. (2006). It simply stated, "Some families say that when a family member becomes seriously ill, other family members suddenly "come out of the woodwork." This means that family members who were not previously in regular contact suddenly become more involved. How much has this occurred as a result of your family member's illness?" Respondents were given a 5 point response set (1= not at all to 5=very much). During analysis, this variable was dichotomized to indicate whether they experienced "coming out of the woodwork" at all or not at all (0=not at all, 1=yes—a little bit to very much).

Contributing Factor Variables

Death Anxiety: Difficulty Integrating Death Awareness

Death Anxiety: Difficulty Integrating Death Awareness was measured through

one survey item, which asked respondents to utilize a 5-point scale (1=strongly agree to 5=strongly disagree) to respond to, "thinking about my family member's death is very difficult for me." The item was reverse scored for direction, so that higher scores on this measure indicated higher levels of difficulty. Though the original intent was to utilize the Death Attitude Profile—Revised, fear of death subscale (DAP-R) (Wong, Reker, & Gesser, 1994), upon further reflection, the single item measure was a better conceptual fit for the study. The DAP-R measures general fear of death, whereas the aim of this analysis was look at anxiety specific to the patient's death. As expected, though, the single item measure correlated highly with the DAP-R (r =.520, $p \leq .001$) supporting its construct validity.

Family Asserting Control

Family asserting control was measured through one survey item, which asked respondents to utilize a 5-point scale (1=not at all to 5=very much) to respond to "As you think about your family since your relative was diagnosed with a life-threatening illness, how much do any family members make decisions about care provided that other family members did not want?" As such, higher scores on this measure indicated higher levels of family asserting control.

Communication Constraints

Four items embedded in the Family Assessment Device (Miller, Epstein, Bishop, & Keitner, 1985) were utilized to measure communication constraints. Respondents were asked to use a 5 point scale (1= strongly agree to 5 = strongly disagree) to answer

the following items: “We cannot talk to each other about the sadness we feel,” “We avoid discussing our fears and concerns,” “We can express feelings to each other,” and “We confide in each other.” Two of the items were reverse coded for directionality, and higher scores on this measure indicated higher levels of communication constraints. A reliability check of this scale revealed an alpha of .82, with item to total correlations ranging from .54 to .71.

Qualitative Analysis

The intent during qualitative analysis was to gain insight into the dynamics surrounding family conflict at the end-of-life through analyzing descriptions provided by hospice professionals and family caregivers. Data was analyzed as it was collected using the constant comparative method (Creswell, 1998; Glaser & Strauss, 1967). During initial analysis the researcher began to wonder if hospice professionals may view conflict differently than family caregivers, so a decision was made to conduct a separate analysis for each perspective. It was later discovered, though, that staff and caregiver perspectives were largely congruent, so the final product of analysis was one conditional matrix displaying the conditions influencing the central phenomenon, family conflict, from the perspectives of hospice staff and primary caregivers.

Strategies used for enhancing analytic rigor and trustworthiness of the findings included (Creswell, 1998; Padgett, 1998; Lincoln & Guba, 1985) 1) auditing that involved careful documentation of the process followed in the development of codes, memos, and analytic decisions, 2) member checking whereby the agency staff reviewed

and validated the analysis, interpretation, and conclusions, 3) searching for disconfirming evidence, which involved combing the data to disconfirm various assertions made as a result of the analysis, and 4) peer debriefing, a co-coding process involving ongoing comparative analysis and discussion of intersubjective agreement between the PI and a co-researcher with expertise with the subject matter and analytic methods employed.

Dimensional analysis, a method to the generation of theory was used to develop the visual matrix of family conflict at the end-of-life. In contrast to grounded theory, which carries no theoretical assumptions, dimensional analysis assumes concepts are defined from an implicit perspective, contextually situated, and socially constructed (Caron & Bowers, 2000). Consistent with its philosophical foundation of symbolic interactionism and theoretical underpinnings of natural analysis, dimensional analysis allows one to derive meaning through the analysis of the component parts of a phenomenon (Kools, McCarthy, Durham, & Robrecht, 1996; Schatzman, 1991). According to Schatzman, "to tell a complex story, one must designate objects and events, state or imply some of their dimensions and properties, provide some context for these, indicate a condition or two for whatever action or interaction is selected to be central to the story, and point to, or imply, one or more consequences" (p.308).

Dimensional analysis can use a wide variety of data, depending on the phenomenon under investigation, including field notes, interviews, focus groups, and published literature (Trotta, 2007). In addition to being utilized in a previous study of family conflict at the end-of-life (Kramer et al., 2006), dimensional analysis has been

used to examine varied human phenomena such as the experience of neutropenia (Crighton, 2004), the perspectives of female nurse administrators in Japan (Brandi & Naito, 2006), and the concept of palliative care in the nursing home setting (Trotta, 2007). The dimensional analysis in the current study relied upon data generated from in-depth interviews of primary caregivers and focus group meetings, which were analyzed using an interactive, three-phase process described by Kools et al. (1996).

The first phase, *dimensionalizing and designation*, a form of open coding, involved the designation or labeling of data chunks in an attempt to identify and name the multiple dimensions involved in family conflict. Notes were made in the transcript margins, identifying potential themes/dimensions associated with family conflict and Microsoft word files were started to organize these potential themes/dimensions. At this point, the researcher attempted to address the question, "what all is involved in family conflict at the end-of-life?" without consideration of the relative importance, relationship, or meaning of specific concepts. This process was conducted until the major aspects of family conflict appeared to be reflected, indicating a "critical mass" of dimensions.

The second phase consisted of *further differentiation* in which dimensions were clustered into families of categories or concepts reflecting various aspects of family conflict in an attempt to provide meaning. Excerpts from transcriptions were cut and pasted into different Microsoft word files representing each of the dimensions of the explanatory matrix with transcript number, page number, and potential code name following in brackets. Explanatory matrices were used to differentiate dimensions into

various conceptual components such as context, conditions, processes or contributing factors, and consequences. Code names from each Microsoft word file were compiled into a list and then reviewed, condensed, and renamed if needed. Theoretical saturation was achieved when a consistent level of repetition regarding concepts and their relationships became evident.

In the third and final phase, a *reintegration* process was used to synthesize the dimensions and their relationships by systematically reviewing the data to document evidence of the major dimensions and to verify the conceptualized relationships between these dimensions. The researcher went back into data to look for excerpts to verify each code chosen and to search for disconfirming evidence. Here the patterns and relationships were described in narrative form (Schatzman, 1991).

Additionally, written responses to the questions of "family conflict is…" and "I have seen family members disagree about…" that were asked of staff during focus group sessions were content analyzed. The final product of this analysis was a comprehensive list of things that family members disagree about when caring for a dying relative.

CHAPTER 4—FINDINGS

Survey (Quantitative Findings)

Sample

Table 1 below presents the background characteristics of the sample. The sample consisted of 161 hospice family caregivers whose ages ranged from 24 to 92 years, with a mean age of 59. The majority were female (83%) and they were almost exclusively "Anglo" (99%). A vast majority (94%) had earned a high school diploma or beyond, with many having earned various levels of college degrees (31%). Only 17% of respondents reported household incomes of less than $20,000, with most falling in the $20,000 to $50,000 range. Most respondents were either employed in some capacity (53%) or retired (41%). Caregivers were related to their care receivers in various ways, with the majority being children (i.e. sons, daughters, son-in-laws, or daughter-in-laws) (55%) or spouses (i.e. husband, wife, significant other, or life partner) (27%). Caregivers reported assisting their family member from less than 1 month to 708 months, with a mean of 71 months, and 19% reported currently caring for other family members or friends.

The care receivers, or patients, ranged in age from 6 to over 98 years, with a mean age of 80. Patients were more equally divided in terms of gender, with 43% being male and 56% being female. Forty-eight percent were living in their own home or the home of a family member, with the remainder living in other professionally operated settings such as nursing homes, assisted living centers, group homes, or hospice facilities. Less than half of the patients (33%) resided with the respondent. Typical for hospice programs

nationwide, the largest percentage of patients had cancer as a primary diagnosis (43%) with the next highest categories being heart disease (17%) and Alzheimer's/dementia (11%).

Table 1. Demographic and Background Characteristics of Family Caregivers (*N* = 161) and Patients

Caregiver Age in Years [Mean (standard deviation)]	59	(13)
Patient Age in Years [Mean (standard deviation)]	80	(14)
Duration of caregiving in months [Mean (standard deviation)]	71	(106)
Caregiver Gender		
Female	133	83%
Male	27	17%
Missing	1	.6%
Caregiver Race/Ethnicity		
Anglo	160	99%
American Indian	1	1%
Caregiver Education		
Less than high school	9	6%
More than high school	152	94%
Caregiver Yearly Income		
Less than $20,000	27	17%
Higher than $20,000	118	73%
Missing	16	10%
Caregiver Employment Status		
Retired	66	41%
Employed part-time	19	12%
Employed full-time	54	33%
Not employed	9	6%
Other employment situation	12	7%
Missing	1	.6%
Caregiver Relationship to Patient		
Daughter/son/daughter or son-in-law	89	55%
Spouse/significant other/life partner	44	27%
Sibling/sister or brother-in-law	9	6%
Parent of child	9	6%
Other family and family like friends	9	6%
Missing	1	.6%

Table 1 (continued). Demographic and Background Characteristics of Family Caregivers (*N* = 161) and Patients

Other Caregiving Responsibilities		
No	130	81%
Yes	31	19%
Patient Gender		
Female	91	56%
Male	70	43%
Patient Living Location		
Own/family member home	77	48%
Other settings	84	52%
Patient Primary Diagnosis		
Cancer	70	43%
Heart disease	27	17%
Lung disease	7	4%
Kidney disease	6	4%
Alzheimer's or other dementia	17	11%
ALS	1	.6%
Failure to thrive	12	7%
Other illness	20	12%
Missing	1	.6%

Presence of Family Conflict

Fifty-seven percent of caregivers reported experiencing one or more types of family conflict at the end-of-life. Thirty-five percent noted that there were disagreements about certain family members not pulling their weight to help provide care; 33% noted disagreements about the way certain family members were treating their dying relative; 28% reported disagreements about their relative's illness or physical condition; 27% reported disagreements about health care decisions for their relative; 19% indicated that family members had insulted or yelled at one another; 18% reported disagreements about how money was being spent or being used; 14% reported disagreements about where

their relative should live out his/her remaining days; and 8% stated that there were disagreements about what is meant by "a good death." Overall, levels of family conflict at the end-of-life were relatively low in this sample as evidenced by the mean score of 1.39 (S.D. = .63; range = 1-4.5). Additionally, 48% of caregivers reported some family conflict prior to their family member's illness. Forty-one percent reported serious arguments in the family and 32% reported family members insulting and/or yelling at one another before their family member was diagnosed with a life-threatening illness.

Family Context and Family Conflict: Hypothesis 1

Hypothesis 1 stated that the family context will be associated with family conflict. More specifically, family conflict at the end-of-life will be higher among caregivers who report a prior history of conflict, absent or insufficient caregiving assistance from other family members, more family demands, fewer resources, and less advance care planning. Correlations, t-tests, and an ANOVA were conducted to examine relationships between family conflict and the family context. Table 2 illustrates the intercorrelations for all of the variables involved in this study. For this hypothesis, attention should be directed at variables 1 through 14. Table 3 depicts results of the t-tests and ANOVA conducted for categorical variables relevant to hypotheses 1 and 2.

These analyses revealed that family conflict was higher among caregivers who reported higher levels of prior family conflict (r = .51, $p \leq .001$) and longer lengths of time caregiving for their family member (r = .15, $p \leq .10$). Family conflict was higher among female (t =-2.26, $p \leq .05$) and younger (r = -.28, $p \leq .001$) caregivers, as well as

those with children under 18 years of age living in their homes (t = -2.33, $p \leq .05$). Family conflict was also higher among caregivers who reported less discussion within their family of their dying family member's wishes for care before he or she became ill (r = -.24, $p \leq .01$).

Contrary to the hypothesis, no relationship was detected between family conflict and educational attainment or income of the caregiver. No significant differences were found by caregiver relationship to the patient, location of care, whether or not the caregiver had additional caregiving responsibilities, or whether or not the caregiver was receiving help from family. Additionally, no relationship was found between family conflict and whether or not the patient had completed a power of attorney for health care or a living will. Hypothesis 1 is partially supported.

Table 2. Intercorrelations of All Variables (*N = 161*)

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1 Family Conflict	---											
2 Prior Conflict	.51***	---										
3 Caregiving Assistance	-.08	-.06	---									
4 Caregiver Age	-.28***	-.26***	-.11	---								
5 Caregiver Gender	.18*	.15†	-.06	-.05	---							
6 Caregiver Education	.09	.14†	-.04	-.17*	.11	---						
7 Caregiver Income	-.09	-.02	-.08	-.39***	-.00	.06	---					
8 Location of Care	.09	-.04	-.17*	-.03	-.13†	.15†	.12	---				
9 Duration of Caregiving	.15†	.14†	.08	.11	-.05	.13	-.28***	.22**	---			
10 Presence of Children	.18*	.19*	.18*	-.52***	.03	.10	.10	.02	.02	---		
11 Additional Caregiving	.13	.15†	.07	-.17*	.14†	.12	.04	.12	.04	.17*	---	
12 Advance Planning Discussions	-.24**	-.19*	.14†	.07	-.08	-.00	.06	-.02	.01	-.03	-.06	---
13 Power of Attorney	-.01	-.10	.02	.16*	-.00	.09	-.01	.14†	.07	-.30***	.01	.01
14 Living Will	.02	-.07	-.06	.02	-.13†	.11	.18*	.23**	.06	-.04	-.01	.14†
15 ADLs	.06	.09	-.04	-.09	-.17*	.12	.06	.40***	.06	-.00	.06	.10
16 IADLs	.17*	.11	-.02	-.34***	-.15†	.14†	.19*	.11	-.01	.17*	.14†	.12
17 Coming out of the Woodwork	.13†	.13†	.15†	-.01	-.02	-.05	-.09	-.21**	-.00	.03	-.01	.00
18 Death Anxiety	.02	.10	-.02	-.07	.06	.01	.01	-.19*	.06	.05	-.01	.04
19 Communication Constraints	.45***	.35***	-.08	-.15†	-.02	-.08	.01	.11	.16*	.14†	.13†	-.16*
20 Family Asserting Control	.60***	.22**	.01	-.05	.12	.04	-.20*	.10	.14†	.09	.07	-.07

Table 2 (continued). Intercorrelations of All Variables (*N = 161*)

Variable	13	14	15	16	17	18	19	20
13 Power of Attorney	---							
14 Living Will	.24**	---						
15 ADLs	.11	.12	---					
16 IADLs	-.05	.04	.49***	---				
17 Coming out of the Woodwork	-.01	-.08	-.11	-.02	---			
18 Death Anxiety	-.16*	-.10	-.16*	-.10	.15†	---		
19 Communication Constraints	-.10	-.12	.03	.05	-.04	.04	---	
20 Family Asserting Control	-.03	-.01	.01	.15†	.04	.03	.28***	---

*†p≤.10; *p ≤ .05; ** p ≤ .01; *** p ≤ .001 (2-tailed)*

Table 3. T-tests and ANOVA for Family Conflict and Family Context Variables

	Family Conflict at the End-of-Life		
	N	**Mean**	**SD**
Relationship to Patient			
Spouse/significant other/life partner	44	.06	.14
Siblings/sister or brother-in-law	9	.14	.14
Daughter/son/daughter or son-in-law	89	.13	.14
Parent of child	9	.15	.13
Other family and family like friends	9	.14	.19
(Missing=1)			
F= 1.86			
Caregiving Assistance			
No help from family	46	.13	.18
Receives help from family	112	.11	.13
(Missing=3)			
t= 1.03			
Caregiver Gender			
Male	27	.06	.08
Female	133	.13	.16
(*Missing=1)*			
t = -2.26*			
Education			
Less than high school	9	.06	.15
More than high school	152	.12	.15
(Missing=1)			
t = -1.09			
Income			
$0-20,000	27	.15	.18
Higher than $20,000	118	.11	.14
(Missing=16)			
t= 1.10			

Table 3 (continued). T-tests and ANOVA for Family Conflict and Family Context Variables

Location of Care			
Own/family home	77	.10	.14
Other location	84	.13	.15
t = -1.20			
Presence of Children			
No children under 18	139	.10	.14
Yes children under 18	22	.18	.17
t = -2.33*			
Caregiving Responsibilities			
No additional caregiving responsibilities	130	.10	.14
Yes additional caregiving responsibilities	31	.15	.16
t= -1.63			
Power of Attorney			
No	6	.12	.13
Yes	154	.11	.15
(Missing=1)			
t= .09			
Living Will			
No	30	.10	.16
Yes	126	.11	.14
(Missing=5)			
t= -.30			

*†p≤.10; *p ≤ .05; ** p ≤ .01; *** p ≤ .001 (2-tailed)*

Conditions and Family Conflict: Hypothesis 2

Hypothesis 2 stated that certain conditions will be associated with the contributing factors to conflict and to family conflict itself. More specifically, caregivers who report the "coming out of the woodwork" phenomenon and greater patient care needs will

experience higher levels of death anxiety, communication constraints, family asserting control, and family conflict. Correlation analyses were conducted to examine these relationships. Attention should be directed to variables 15 through 20 (and 1, family conflict) in Table 2.

These analyses revealed that "coming out of the woodwork" did not correlate with communication constraints or family asserting control and correlated with death anxiety (r = .15, $p \leq .10$) and family conflict (r = .13, $p \leq .10$) at the trend level. Patient ADL needs was found to be negatively correlated with death anxiety (r = -.16, $p \leq .05$), indicating that higher ADL needs related to lower levels of death anxiety. Patient ADL needs was not significantly correlated with communication constraints, family asserting control, or family conflict. Patient IADL needs was found to correlated with family conflict (r = .17, $p \leq .05$), signifying that higher IADL needs related to higher levels of family conflict. Patient IADL needs significantly correlated with family asserting control at the trend level (r = .15, $p \leq .10$), indicating that higher IADL needs related to higher levels of family asserting control. Patient IADL needs did not demonstrate a significant relationship with death anxiety or communication constraints. Hypothesis 2 is partially supported.

Contributing Factors and Family Conflict: Hypothesis 3

Hypothesis 3 stated that after controlling for the family context and conditions, contributing factors (death anxiety, communication constraints, and family asserting control) will significantly predict family conflict. Due to the number of independent

variables and the limited sample size, only the family context variables that were significantly correlated with family conflict were entered into the regression equation. The variables found significant at the zero order level included prior family conflict, caregiver age, caregiver gender, length of caregiving, presence of children, and advance planning discussions. In order to test this third hypothesis, hierarchical multiple regression analysis was conducted that controlled for the family context and conditions. The first block of independent variables included the family context variables just mentioned. The second block of independent variables included the three condition variables (i.e. coming out of the woodwork, ADLs, and IADLs). The third block of independent variables included the three contributing factor variables (i.e. death anxiety, communication constraints, and family asserting control). Since listwise deletion of missing data was utilized, the sample size for this regression reflected only observations that had complete data for all of the variables included. When any of the variables were missing, the entire observation was omitted from the analysis, resulting in an analytic sample size of 148.

Table 4 presents the results of the regression analysis which explained 60% of the total variance in family conflict. In the first step of the model, family contextual variables explained 31% of the variance in family conflict, with prior family conflict, caregiver age, length of caregiving, and advance planning discussions standing out as statistically significant predictors of family conflict. In the second step, condition variables did not make a significant contribution to family conflict, explaining only 2% of

the total variance in conflict. In the third step, contributing factors uniquely explained 27% of the total variance in conflict. Significant main effects in the prediction of family conflict in the final model included caregiver age (b = -.00, $p \leq .05$), caregiver gender (b = .04, $p \leq .10$), prior family conflict (b = .02, $p \leq .001$), advance planning discussions (b = -.01, $p \leq .05$), out of the woodwork (b = .03, $p \leq .10$), communication constraints (b = .04, $p \leq .001$), and family asserting control (b = .06, $p \leq .001$). Hypothesis 3 is partially supported. In the final model, communication constraints and family asserting control demonstrated significance in the direction anticipated, while death anxiety did not demonstrate significance.

Table 4. Hierarchical Regression Analysis for Contributing Factors and Family Conflict (N=148)

	Betas		
Variables	Step 1	Step 2	Step 3
Family Context			
Prior family conflict	.38***	.36***	.22***
Caregiver age	-.18*	-.14	-.17*
Caregiver gender	.11	.13†	.10†
Length of caregiving	.13†	.13†	.05
Presence of children	.00	.00	-.04
Advance planning discussions	-.15*	-.17*	-.11*
Conditions			
Patient ADLs		-.01	.02
Patient IADLs		.14†	.04
"Out of the woodwork"		.08	.10†
Contributing Factors			
Death anxiety			-.05
Communication constraints			.22***
Family asserting control			.46**
Total R^2	.31	.33	.60
R^2 change	.31	.02	.27
F for R^2 change	10.67***	1.48	30.11***

*† $p \leq .10$; * $p \leq .05$; ** $p \leq .01$, *** $p \leq .001$*

Focus Groups & Interviews (Qualitative Findings)

Ten discipline specific focus groups were conducted, with six involving nursing staff and four involving psychosocial services staff. A total of 37 staff participated in one or more focus group sessions including 12 nurses, 9 certified nursing assistants, 9 social workers, 3 chaplains, 2 bereavement coordinators, and 2 volunteer/community outreach coordinators. Three of these staff members held additional position titles of patient care

coordinator, director, or admissions coordinator. Of the 37 participating staff, all identified as being White/Caucasian, with the exception of two, who were of Hispanic descent. Thirty-three were female (89%) and four were male (11%). Ages of participants ranged from 24 years to 72 years, with a median age of 47 years. Experience working in hospice ranged from 3 months to 24 years, with a median of 7 years of experience.

Fifteen family caregivers participated in interviews (see Table 5 below for profiles). Fourteen were female and one was male. Ages of caregivers ranged from 46-72 years, and all caregivers were White/Caucasian. The majority of caregivers were the child of the patient, and primary diagnoses of cancer and Alzheimer's/Dementia were most common. The majority of patients were living in either a skilled nursing facility or a group home, with the remainder living in their own home with various levels of support. Comparison of those interviewed to the larger sample of respondents expressing family conflict revealed that the two groups were similar on most study variables. T-tests did reveal that those interviewed had significantly higher levels of conflict (t = -4.737, $p \leq .001$), communication constraints (t = -2.72, $p \leq .01$), and family asserting control (t = -3.54, $p \leq .001$) than those who were not interviewed.

The model resulting from the focus groups and interviews is likely more indicative of families with relatively high conflict. This is due to the screening process employed by the researcher when surveys were received. If multiple interview eligible surveys were received at the same time, the researcher chose the ones with the most

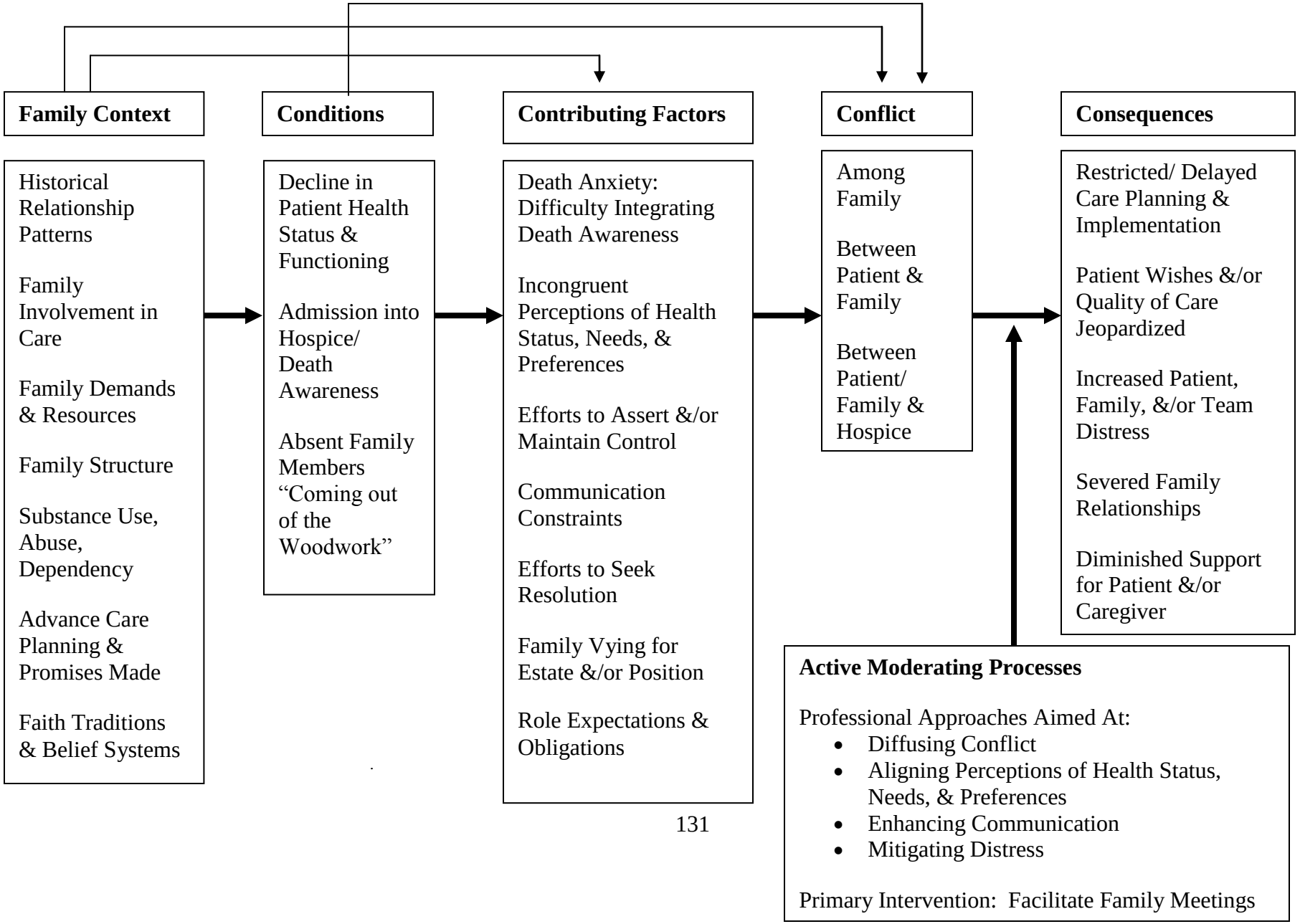
conflict to invite for an interview, with the aim of gaining access to more complex situations. Since communication constraints and family asserting control correlated so highly with family conflict, it makes sense that those interviewed demonstrated higher levels of these variables as well. Further, although hospice professionals were not specifically asked to only discuss experiences with very high conflict, it is likely that they were inclined to think about the more extreme cases encountered in their practice. It is possible that they were not even aware of lower levels of conflict in some of the families that they worked with.

Table 5. Interview Participant Profiles

ID	Gender	Age	Relationship to Patient	Patient Diagnosis	Patient Age	Patient Living Arrangements
1	Female	46	Spouse	Cancer	51	Own home, with caregiver
2	Female	46	Daughter	Creutzfeldt-Jacob's Disease	68	Nursing home
3	Female	62	Daughter	Failure to Thrive	94	Nursing home
4	Female	59	Daughter	Cancer	79	Own home, with spouse and caregiver
5	Female	64	Daughter	Alzheimer's/Dementia	87	CBRF
6	Female	51	Daughter	Alzheimer's/Dementia	88	CBRF
7	Female	53	Daughter	Failure to Thrive	89	CBRF
8	Female	57	Daughter	Cancer	79	Own home, alone
9	Female	56	Daughter	Alzheimer's/Dementia	80	CBRF
10	Female	54	Daughter	Cancer	82	Own home, with caregiver
11	Female	72	Significant Other	Cancer	85	Nursing home
12	Female	53	Daughter-in-Law	Alzheimer's/Dementia	87	Nursing Home
13	Female	47	Daughter	Cancer	83	CBRF
14	Male	47	Son	Cancer	75	Own home, alone
15	Female	54	Daughter	Alzheimer's/Dementia	81	Own home, with private hire caregivers

As previously indicated, focus group and interview data were initially analyzed separately to allow for detection of differences in perspectives. Ultimately, though, few significant differences in perspectives emerged, and only one explanatory matrix was necessary. The explanatory matrix of family conflict at the end-of-life is depicted in Figure 2 below. The dimensions of the matrix will now be defined and illustrated through data excerpts from both hospice professionals and family caregivers.

Figure 2. Explanatory Matrix of Family Conflict at the End-of-Life *(Boelk)*



Defining conflict

Hospice professionals were asked to define conflict during focus group sessions and they did so in a number of ways. The following words were used to describe conflict: outward disagreements, arguments, discord, abuse, verbal challenging of one another, unproductive communication, open expressions of anger, disrespect of feelings, underlying tensions, resentments, distancing, and avoidance behaviors. The definition previously used by Kramer et al. (2006) and Kramer et al. (2009) seemed to accurately capture these sentiments and during member checking staff members were asked to comment on its appropriateness. This definition, "interpersonal tension or struggle among two or more persons whose opinions, values, needs, or expectations are opposing or incompatible" was verified by staff as accurately reflecting their views and experiences. Examples of both outward (hostility, arguments, insults, open aggression) and subtle/underlying (tension, resentment) conflict emerged in the data, and the above definition encompassed both forms.

Professionals and family caregivers discussed conflict that was rooted mainly in the family context (prior family conflict) and that which was a result of the end-of-life situation. They expressed that prior family conflict is more prevalent and less amenable to change than that which relates directly to the end-of-life situation. For example, one social worker noted,

> I'm always surprised how most of our conflict isn't about end-of-life decisions. I very rarely have someone say "no, why are they doing Hospice?" It just hardly ever happens. I can't even think of a case.

A nurse further indicated:

> I see it as expressing their previous relationship issues. All the stuff that has gone on in the past that we are not aware of kind of gets expressed at this point of crisis…it's built over a long length of time.

Family caregivers also made this distinction, illustrated in the following data excerpts:

> Most of those issues happened before we could get hospice involved. Most of it was happening when all we were dealing with is the progressing Alzheimer's…by the time we got the cancer in there most of those have been resolved or eased up.

> I don't look for them [the other siblings] to change a lot anyway, and if they do change until mom dies…they'll just go back to the same thing anyway. We're never going to be real close.

Forms of Conflict

Three main forms of conflict emerged from the data: 1) conflict among the family, 2) conflict between the patient and family, and 3) conflict between the patient/family and hospice. Conflict among the family is illustrated by the following quote from a hospice professional:

> A family with a very elderly matriarch…whose children were scattered all over the country…a large family that was very chronologically scattered….siblings from 40-something to 60-something, and had had some considerable conflict over caregiving for mom. And some of that was exacerbated by distance and some of that by personality type, but…also having very different relationships with mom. So that was a situation where the nurses had seen a lot of that conflict as different siblings were there for different visits, and the sibling that had been the long-time care giver for several years, who lived the closest, sort of got some control usurped as new siblings became more actively involved as mom's health declined.

Conflict between the patient and family is illustrated by these quotes, the first from a hospice professional and the second from a caregiver:

> The patient wasn't accepting of her situation and kind of started yelling… she was kind of pushing her daughter away. Her daughter wants to be there, but she

> just…can't take her mother anymore because of that, and that she doesn't want to visit as much now.
>
> If I get a movie like one I did the other night, the dog died and I start crying, he [father/patient] just comes unglued. "We're just not going to watch any more movies if it's going to offend you like that. That is so stupid," he said. "It's just unbelievable." He just goes on and on…That's when I explained it and said, "dad, I'm really homesick…it's been a long time since I've been home."

Conflict between the patient/family and hospice is illustrated in this excerpt from a daughter caregiver:

> Hospice is end-of-life and…I still want to try to heal him. I still want to try to get the vitamins and minerals to give him his energy and to get the good foods in him…if he's got something that's bothering him, let's see if we can get him something to help with that…they might be missing the boat where there could still be a healing…He's really swollen in the lymph glands…I talked to one of the hospice nurses and "oh we don't want to use that too much." Well, what difference does it make if it helps and if he doesn't have that long anyway? It's like saying, "well, you got 60 days, I don't want you to get hooked on narcotics." If it eases his pain, it doesn't make any difference if he's hooked on it or not.

Examples of conflict between the family and another provider (i.e. nursing home staff) and between hospice and another provider (i.e. home health staff) were also given, but were not discussed fully enough to include in this model. A number of examples of internal conflict also emerged, but did not fit the definition of conflict utilized for this study, which focused on relationships between and among people.

Topics of Family Disagreements

Table 6 depicts the various things that hospice staff perceived family members to disagree about. Fourteen general theme areas emerged from the data, and descriptors given by staff are provided in the right-hand column. These ideas were affirmed by family caregivers during the interviews, as they provided in depth examples of such

disagreements.

Table 6. Topics of Family Disagreements

Topic	Description
Caregiving	How to provide, what type/level of care is needed, quality of care, who gives better care, what to feed or not feed the patient
The Patient's Condition	Participation in activities, patient activity level
Treatments & Procedures	Fighting disease versus "giving up," treating or not treating infections, what tests/procedures the patient should/should not have, use of the ambulance, use of emergency room
Medication Use	What medications should/should not be given, Sedation versus keeping patient alert
Life-sustaining Measures	Artificial hydration/nutrition, ventilation, code status, prolonging life versus comfort measures
Enrollment Decisions	Involvement of outside help (including hospice)
Location of Care	Where the person lives and receives care
Post-death Decisions	Funeral planning, burial, handling of cremains
Family Roles & Responsibilities	Who is making decisions, how workload is shared, who will take leave from work, who will patient live with, who will be main contact person, who will serve as power of attorney
Family Involvement	Visiting/not visiting patient, who is providing care and who is not doing their fair share
Finances & Estate	Money, distribution of property/possessions/estate/inheritance
Communication	What to tell the patient, what to tell the children
Spirituality	Appropriate faith traditions & rituals
Coping	Who is coping/not coping appropriately

Family Context

Conflict was not described as a stand-alone phenomenon, but only derived meaning within the context of the family environment. In many instances described, families had more than one of the characteristics identified below. In some instances conflict rooted in the family context became more obvious and/or pronounced as the family was forced together around the end-of-life situation.

Historical relationship patterns relate to communication norms, prior conflicts and personality clashes, relationship quality, allocation of power within the family, gender roles, and resentments from prior death events. Historical relationship patterns involve how families interact with one another prior to illness onset and may influence how family members approach one another when faced with an end-of-life situation. This quote from a hospice professional illustrates how historical relationship patterns influenced the ability of some family members to offer assistance at the end of life:

> We learned something about dad's relationship with the daughter that was really pretty reveling…it stemmed back to a time of conflict forty some years ago, when this baby was born and was colicky. And mom…patient, who had already had her hands full with all her other children, just kind of put this baby down on the bed and said, "I can't take care of her."…And so he came in from the barn, picked her up, and that was his child. He nurtured that child all the way through and, and that was his job as the parent. So now fast forward forty some years. He's alone. Where are all the other kids? They're not coming to help dad, just this daughter….I think she was doing it on her dad's behalf…She had a very strained relationship with her mother.

Each family caregiver interviewed discussed the impact of historical relationship patterns on the present situation in some way. They shared powerful examples of pain they observed or experienced in the past due to relationship patterns. Examples of hatred,

jealousy, collusion, secrecy, power and control, favoritism, harsh judgment and criticism, gender role expectations, violence, criminal behavior, developmental issues (i.e. insecure attachments, dependence) and financial, sexual, and physical abuse emerged from the data. The following quote is from a daughter, who despite being one of four children was caring for her father alone. She explained that her brother previously had financially taken advantage of her father and had neglected his care needs, one sister was not involved due to the father's attempts at sexual abuse during childhood, and the other sister would not speak to her after a recent argument. This caregiver describes the complex family relationship issues that can have bearing on how the family responds at the end-of-life:

> My dad always hated me, so he never gave me anything but kicks in the ass or a hit in the face…his graduation present was a suitcase and told me use it before he got home from work that night…he told me once I was garbage, no matter what I do, I'd always be garbage. You don't know how many times I often thought, "garbage girl is taking care of you now, dad!"…I'm grateful that we finally have something…he knows I'm his daughter and all, but he doesn't know I'm the one he used to kick around…There was sexual abuse in the family that my dad did toward me for quite a few years and he started in on my sister…to this day I can hardly stand to be in the same room alone with him…but you got to just let go of the past sometimes…you got to step up when you're needed.

Another caregiver spoke of the impact her parents' divorce over twenty years back had on the family when attempting to care for their terminally ill mother:

> These two people hate each other…and that makes for a lot of tension…in the last twenty months I haven't really had any interaction with my dad at all…he's not going to be wanting to spend any time with me because he knows that I'm taking care of my mom…my siblings are trying to strike a balance between my parents…we know that mom is dying and we want to spend some time with her, but we know that dad doesn't see that as being, it's you're for me or against me, so if you see her, then you're against me. And that could be one reason that

> they're not as supportive as they could be…because of the dynamics…wanting their kids to know both grandparents, that might have put them in a tougher situation…it's pretty cut and dry for me…I don't have kids that have to see my dad.

Family involvement in care may vary from none to extensive and may influence knowledge of the patient's health status, family relationships, and their experience and perceptions of burden regarding care provision. This concept is illustrated in the following statement by a hospice professional:

> …How associated, how close were they with that dying member previously...is it somebody who's been three hundred miles away and they haven't seen them only once or twice a year? And now all of a sudden this individual is dying and they are not able to be there, versus someone who's there twenty four seven…that causes conflict because the people who are there all the time are envious. In that…they have to be there all the time but somebody else doesn't have to be…So it's kind of the burden as "I have to take this all on myself."

Every family caregiver interviewed discussed how varying levels of family involvement in care formed a foundation for family conflict, as illustrated in the following quotes:

> She [sister] promised when I went into this as POA that I would have her help and assistance. She has not helped once…I don't have anybody…she don't come up and see him [father/patient]. She lives 7 minutes and she won't. Takes me an hour and a half. I get very frustrated. I tell everybody, "if you want to go up and see him, he won't know you, but he sure would love to see you."

> I have a middle sister who is not involved at all and never has or wanted to be or shows any compassion…we have tried to reel her in, every time we say, "[Name], we need your help," we have to ask for it…it's never offered. It's based upon well she's busy…she gets very upset with us when we ask her to do things. I have been sworn at. I have been hung up on. I've had excuses as to where "well I have someone else at work who's going through cancer." And I said, "your mother has cancer, [name]."

Family demands & resources refer to how families face varying life demands as well as resources available to them. They experience differing degrees of economic

resources, other work and caregiving responsibilities, physical and mental health issues, and knowledge of the health care system. This example shared by a hospice professional illustrates how financial struggles can influence family conflict at the end-of-life:

> There were money issues because if she [patient] were to go to a nursing home then her disability check wouldn't be coming into the family anymore to help them pay the rent on their apartment, so he [husband] wanted her to just stay home, period. She wanted to stay home period, but it wasn't safe. So then of course the nurse looking out for the patient's safety got pretty forceful toward the end and "you really must go to the nursing home." She agreed. She went. Husband not happy according to the wife then started taking up with an old girlfriend and so the marriage relationship just wasn't what it had been obviously when they were living at home together…They had lots of fights during the time she was on hospice anyway. At one point cut up her DNR band and said "now you'll have to take care of me forever and keep me alive."

An additional hospice professional quote illustrates how a family member's mental illness can serve as an additional family demand, fueling conflict among family as well as with hospice:

> …a patient was in the nursing home and the family was there all the time but the family member who was the Power of Attorney…wasn't there all the time and another daughter was there constantly trying to make every decision and…she would literally lie…to get us to talk to her and not call the power of attorney and created scenarios where [the nursing home's] trying to do this to my mother…she'd tell us one thing when we talked to her directly on the phone and then we'd talk to the nurse we'd get a different story completely. And when we'd go in to have a meeting the story would change to a third story. "I never said that…that never happened, I didn't do that."…And then we'd go "we were all standing here when you said that"…you can sit there and argue about it all day long but the fact is she denied that. But…she had a diagnosed a personality disorder and I can't remember which one it was because she had symptoms for so many of them.

Family caregivers also described various family demands and resources that provided context for the end-of-life situation. This caregiver described how her work

responsibilities, coupled with her sister's and brother in law's expectations, fueled conflict:

> They told me and my younger sister that we should quit our jobs and stay home and take care of mother. And that's non-logical because we both need to work. I'm almost close to retirement. My sister's got five years. I mean you can't give up your job…that's where the stress started…and they accused me of elder abuse because I wasn't there all the time…I said, "you guys, be logical. I can't afford not to work."

A number of caregivers described how their own background with the medical system, while serving as a resource to the family, placed additional demands upon them and set them apart from other family members in terms of knowledge, skill, and comfort with end-of-life care. This daughter-in-law of the patient described her situation in this way:

> I'm an RN by training…and I think sometimes that makes me, I want it done right…It was easier to give in, it was easier to hand it all over because I knew what was going on…when their dad died, we had this care conference and we all got together…and the doctor says, "well, what do you think that his condition is?" And they all looked at me and they said, "well, what do you think?" I'm like, "I don't know. This isn't my job."…and I think that's probably one of the reasons they let me take over here too is because they just think I know everything.

Family structure refers to how the family is comprised. Large families; families who have experienced divorce, separation, and/or remarriage; families with young children in the home; and families in which one or more members live at a distance were identified as more at risk for conflict. This quote illustrates how "step family" relationships may influence how family members relate to one another as they come together to provide care to a dying relative:

> We had a gentleman who was dying. He lived with his girlfriend for years. It was in the family home. When the daughters came, they took over completely. They totally disrespected this woman's home and she retreated because she didn't feel

comfortable standing up for herself.

The above noted family structure issues also manifested during the family caregiver interviews. One daughter-in-law discussed the difficulties that large families can pose in end-of-life caregiving, comparing her family of origin to that of her husband, which was involved with hospice at the time of the study:

> There were 9 kids…I think sometimes the bigger the family the harder it is to stay close. You have more chance to back bite. I think smaller families don't have that same opportunity. Like my sister and I are the only two girls; we have no one to go back biting to, and I think maybe in the bigger families it's harder because it's easier for one to talk to this one and that one to talk to that one…and things get stretched or changed a little bit or everybody adds their own little nuances to the messages, and I think that might be part of the problem.

Substance use, abuse, dependency involves families in which there is a history of use, abuse, and/or dependency on alcohol and/or other drugs. This excerpt from a hospice professional illustrates how a history of substance abuse, coupled with other family dynamics, can influence how family members interact when faced with an end-of-life situation:

> …a gentleman who was dying of cancer in his mid- to late-forties, who was living with a brother. The brother happened to be a police officer of a small town, and the gentleman who was dying had a history of alcohol and drug abuse, and he was divorced and he had custody of the teenage daughter who was living also in the home…Conflict with the family, I think, really was, again, long standing situation…for one you have a brother who's a police officer and you have his half-brother who's an alcoholic and drug abuser who years and years and years of his brother who's a police officer trying to clean him up, make him go straight. Just kind of always, "jeez, he's always just the trouble one in the family… jeez, he just can't get his act together." And now here we are at the end of his life and caring for him…"Jeez he brought this on himself and now I'm taking care of him" and then that true loyal brother that, "He's my little brother. I love him. How am I going to take care of him? And, gee, now I'm telling him what to do again and he's still telling me, go beat off." So there was some, just very tense dynamics

> that were long-standing that we as a hospice organization had to insert ourselves into, figure it all out in a fairly short amount of time to allow our goal, which was a peaceful death at home.

Family caregivers also described the role of substance use in family conflict at the end-of-life. One woman whose husband was terminally ill described a significant history of alcohol and other drug use by her husband and how his relationship with substances set the stage for family conflict at the end-of-life:

> He [husband/patient] was locked up for two months, so I took two months away from his life. If he wouldn't have screwed around with the pills they gave him to make him comfortable and start getting violent, he wouldn't have been locked up…he liked Xanax and how he deals with problems is takes a bunch of pills and then…he's just out of it…And that one night I got home from work…I just had it…and I called and they locked him up and he was on probation from the same thing from before, and his probation officer revoked him…for abusing the drugs and…he wasn't hitting me but he was verbally abusing…when he was taking them he'd get so violent. He'd forget who he was talking to…and every little thing would set him off…but they [other family members] don't understand that. They don't see it day after day after day.

Another family caregiver shared this example of the impact of substances on the present situation:

> I know my little brother is an alcoholic. I understand that. My older brother, however, I think his brain is fried on whacky weed, and I don't know how much that has to do with what his personality is, and so I kind of try and say he's fried and he's just not any good, he can't help it, but it's very hard at this point when mom needs, and he's not there, then it bothers me.

Advance care planning & promises made involves the extent to which family has discussed and realistically prepared for end-of-life prior to disease onset, and who within the family has been granted official decision-making authority for finances and health care. In some families it may involve promises being made regarding avoiding nursing

home placement, as indicated in the following quote from a hospice professional:

> One of the spouses promised the other that they never would put them into a nursing home. And then when the time comes and they can't do the cares. That is a real hard thing for families…because they promised and now they can't do it… So they say, "we got to do this for mom." And then the other part will be saying, "no we can't. We promised her. We need to"…, but yet there are not enough caregivers so sometimes they don't have a choice. That's a big promise to make to somebody…sometimes families don't understand that, mom or dad can't take care of the other one there…mentally and physically.

One family caregiver described how her role as Power of Attorney for Health Care has lead to conflict within the family:

> I made a family meeting. I called them [siblings] to my house…and I said, "o.k. here's what we can do for mother at home. Let's try to keep her at home as long as we can." Well, she [sister] said I cut and dry everything. "Now you throw it in my face." "I take care of things." And I told them after that, because she told me that, "if you want something done today, you tell me today. If you want it done a week from now, you tell me a week from now." Because when it has to be done, I will do it…She thinks I make decisions, and which I do because my mother gave me the authority to make the decisions for her…so I want to make sure she's taken care of. But she just sees that as me in control…I didn't want this power for health care, but nobody else wanted it.

Faith traditions & belief systems involves differences in spiritual practices and beliefs within the family. This quote from a hospice professional illustrates how such differences within the family can be an impetus for conflict:

> I've seen it sometimes when the parent is older and a very traditional Catholic or a very traditional Lutheran and the kids are Fundamental Christians…and they're actively trying to convert…some of the conflict can surround the funeral ritual and the planning for the funeral, whether the patient has chosen cremation and the family members do not believe in cremation…We've seen situations where there's conflict amongst the siblings as well as trying to convince the patient to change their mind on what they choose or funeral plans that the patient already has in writing and now the family wants to do something different.

One caregiver shared how differences in beliefs, coupled with a lack of advance

planning, had the potential to lead to conflict within her family:

> There's possibly going to be a problem. Mom wanted to be cremated. My little brothers are o.k. with it…but my older brother believes you go out of this world the same way you came in…and I'm like, "well mom wants to be cremated. I'm the executor of her estate, so pretty much that's what's going to happen," and I know it's going to cause problems all the way around, because I'm sure her sisters will just be mortified…three days after my dad died…I begged her, I said, "let's go down to the funeral parlor and make all the arrangements right now…because mom I will be so upset that I want to make sure you get everything you want."…Well, that didn't happen…it's just going to hit the fan because sometime we're going to have to…

Conditions

Conditions "are dimensions of a phenomenon that facilitate, block, or in some way shape actions and/or interactions" (Kools, 318). Two predominant conditions and one frequently co-occurring condition underlying the processes of family conflict at the end-of-life manifested during the analysis.

A *decline in patient health status & functioning* occurs and may include changes in physical and/or cognitive/psychological functioning related to a life-threatening diagnosis and typically results in increased care needs. Health status and functioning may fluctuate over time, with the disease trajectory being uncertain in some cases. The following quote from a hospice professional illustrates this condition and how it can set the stage for conflict:

> Changes in the patient's behaviors, when they're sleeping more or they become agitated... restlessness…and that's…where…different expectations of different family members…whatever preconceived ideas or expectations they have, if it doesn't play out that way, one person can be more accepting of what is happening than the other one who thought was going to be different somehow…So it's a lot about expectations…most commonly it's about the dying process.

One spousal caregiver described how a decline in the patient's health status caused family to come together and resulted in tension surrounding the will:

> He was in intensive care, his first chemo, it was too much chemo and then he was on valium at the time and it interacted…and then I called them [patient's children], I said, "you guys got to come up. We don't know what's going to happen. It could go either way." So they did come up, and then [one daughter]…asked [patient], "what are you going to leave me dad?"…and it's like we aren't even at that point…my daughters would never even think of that.

Another caregiver described how a decline in the patient's functioning, coupled with incongruent perceptions regarding where the patient should live resulted in conflict among siblings and a potentially permanent rift in the relationship:

> It didn't take us long to know she could not live alone…she put the frying pan full of water and burned up the frying pan, so we started taking care of her…that went really well for a while and then all of a sudden they [other siblings] said she needed to be in a nursing home. Well, they pushed it so much that finally we locked them out of the house. I mean they called social services and said we were abusing just cause they wanted her in the nursing home…so they no longer speak to us.

Admission into hospice/death awareness signifies a transition into palliative versus aggressive care, introduction of new services and supports, and for most families, more clear awareness that death is approaching. This quote from a hospice professional illustrates how this transition can shape family conflict:

> Any transition time is a time when conflict can arise pretty easily if the foundation for it is there. So…making the transition on to a hospice program, you'll have some families split over wanting to be on a hospice program…I can think of one where…three kids were extraordinarily comfortable with it. Mom was extraordinarily comfortable with it. The father was the patient, and the…son was extraordinarily uncomfortable with it and very much against it. Wanted to be there but even at the time of death when the hospice nurse came, went upstairs and would not interact with the hospice personnel at all. Then pretty much systematically refused to have contact with anyone, even the mom that he had had

> a decent relationship with…Sometimes those transitions just…kind of spurs the conflict and it doesn't die easily after that.

One caregiver described how the transition to hospice and increased death awareness among the family served as a condition facilitating family conflict:

> All of us helped out at one point, but now that mom has been on hospice…my older sister…chooses not to be involved in my mother's care. In fact, she doesn't talk to me at all. She was at that meeting that day with hospice and she did not say a word about anything. The phone call basically that she said is, "when you do your scheduling next time, you don't have to schedule me, because I may make the wrong decision and I don't want to be responsible for that." And she was talking in reference to…at this hospice meeting…they said "we always want you to call hospice first,"…and I don't know if that bothered her or if it's just her way of coping…We had to drive home at this meeting, it's like we're trying to make mother comfortable, we're not trying to save her life anymore…my family has a hard time dealing with it, so [my sister] chooses not to be involved anymore.

Absent family members "coming out of the woodwork" is a frequently co-occurring condition, which refers to uninvolved and/or distant family members "arriving on the scene" upon learning of the deterioration in the patient's condition and impending death. Family members may come out of the woodwork to give or gain support, attempt to aide in decision-making, or to just be present with the patient and family as illustrated in the following quote from a hospice worker:

> Sometimes I'll see where in a family that maybe a son or daughter had nothing to do with their parents for lots of years and then all of sudden they're dying and they're right there for everything and trying to make all the decisions. And when the other members were around and close and were helping. And then all of a sudden this one comes in and wants to take over the whole thing, and that's a lot of conflict there…Like all the decisions. I had a lady that just changed her will. She doesn't see her son. She hasn't seen him in years. And she just changed her will and took him right out of the will because he doesn't call her. And when he does call her, he calls for money…Unresolved issues. And then all of a sudden they come to head because this person's dying and they want.

One caregiver described the "coming out of the woodwork" phenomenon in the following way:

> She [patient/mother] moved up here the weekend before Halloween…The assumption was automatically made that "mom's there, Thanksgiving is at your house." And so I found that all of a sudden I'm getting ready to host this big Thanksgiving dinner and mom's coming over and everyone wants to see her. And I've got five overnight guests, and then, "oh and by the way Christmas is at your house"…I know part of the survey had asked me how people kind of come out of the woodwork to help with things. This wasn't coming out of the woodwork to help. This was, "good! Now we have some place to stay when we visit mom"…and I don't think I've ever been able to come up for air since.

Contributing Factors

The conditions described above were not uniformly followed by conflict. However in situations in which one or more contributing factors developed, conflict was evident. These contributing factors may be thought of as "intended or unintended actions or interactions…impelled by these conditions" (Kools, et al., 1996, p. 318). There were seven contributing factors that emerged in the data.

Death anxiety: Difficulty integrating death awareness involves situations in which the patient or family has difficulty accepting the terminal nature of the patient's condition and/or seeing the patient in the state they are in. It may involve general discomfort with death and dying on the part of one or more family members. One hospice staff member shared this example:

> …we have that situation right now where the mother is losing her appetite and she doesn't want to eat but the daughter is forcing her to eat and she doesn't want to listen to anyone about it… And mom, she's in her 90's, she's got a cancer, she's losing her appetite…all the classical signs of end of life…she's not imminent but she certainly is starting to fail and her daughter just doesn't see it….

One son shared how his brother's death anxiety contributed to conflict within the family:

> He's got a hard time dealing with it, with the fact that she's dying. He doesn't like to see it, so then he'll call her, but he won't go up there, and he actually owns the house she lives in. And he's kind of one that's on his own. He does what he thinks is best for him and the heck with everybody else, so that when the rest of us try to do stuff for mom, he usually doesn't want to help or doesn't pitch in and then it pisses the other ones off…between him and my sister, there's been a few [arguments]…when she hears that he doesn't do some stuff…it festers and festers until she comes home and they're both stubborn so when they click heads, the click heads.

One significant other shared how the patient's daughter's death anxiety contributed to conflict and difficulty making decisions:

> When he had several surgeries…we'd discuss it with the family, "well, what do you think? Pa's going to have this surgery now."…"Oh he could die! He could die!" [patient's daughter] says. "Well yeah," I says, "he could die sooner if he doesn't get them done."…And [another daughter] would say, "I think you are right. I think he'd have a better life if he had this done." And [the first daughter] would say, "Nah, I don't agree. He could die. He could die."

Incongruent perceptions of health status, needs, & preferences may include differences in views about patient abilities, health status, care needs, and care setting, as well as preferences for end-of-life care and funeral planning. Incongruent perceptions often stem from differences in knowledge/information about death and dying and/or the patient's health status. They may also stem from past experiences that have generated ideas and expectations about what the dying process should be like. This excerpt from a hospice professional illustrates how incongruent perceptions can fuel conflict within the family and between the family and hospice:

> …the wife was very on the same page as hospice…the family was divided. There were four kids. Two of them were very pro-hospice. This is what dad wants. Dad's getting good care. He's comfortable, let's let him die peacefully. And the

> other two were, you have to fight every step of the way up to the last minute and you should be in a hospital getting aggressively treated and IV fluids, and…we tried to explain to them that this would physically create more problems…they just did not accept that information because it wasn't what they initially believed and they were not going to be persuaded…these sons were so belligerent with the hospice staff when we were there and like, "you are wrong and you're killing my dad and this is murder" and…this kind of thing and it's like, "your dad signed up for this. Your dad knows what he wants and it's not killing him, it's allowing him to die"…They all said what a great dad he was and how much they loved their dad. They just had completely different views on what end of life care should entail.

One daughter shared how incongruent perceptions about her mother's care fueled conflict among the siblings:

> They thought we were just going to take mother to the clinic and get this x-ray of her back…any kind of argument really revolved around that because it was like, well "we're just going to have to do this. We're going to have to take her to the clinic, no matter what. We're going to find out where this pain is coming from, and then we're going to do something about it." And it's like, "well, let's step back here a minute. Why are we doing this?"

One daughter-in-law shared how incongruent perceptions about care needs and location of care spurred family conflict:

> When we took her to the hospital the last time, I had called…and said, "[mother-in-law] is in the hospital, on IV's," and [patient's son] comment was, "why didn't you just let her die?" Which, you can't let somebody die just because they have pneumonia…we weren't at that stage yet…so the disagreement has been, they have always sort of wanted to put her in the nursing home and let her go, and we've never felt that way. And now we're good with what's going on, and I think they're very happy with this, but now the rift is, you know, it's too late.

Efforts to assert &/or maintain control involves family attempts to dictate decision-making and/or care planning, while not allowing others to fully participate. It also involves patient attempts to "call the shots" in the face of diminished independence and ability level. One staff member shared this example:

> We had a lady that was imminently dying at a care facility. There were two adult twin daughters that lived in Milwaukee, and then a daughter that lived here. The daughter that lived here pretty much took control of everything, finances, where mom lived, all of it without consulting the twins who were very close…So when she was dying the communication was still hard for the family members, cause they still held a long term resentment of all this, cause they didn't have much involvement, they weren't allowed to help with decisions for their dad who died a couple years earlier and now they weren't allowed to help with the decisions for their mom, even being listened to by this one daughter. They came up, they were able to spend time with her but they had to actually ask the daughter if it was ok if we vigiled and vigiled separate from them and it really brought up a whole lot of hurt feelings.

Most caregivers interviewed also shared examples of efforts to assert or maintain control as a contributing factor for conflict, as in the following statements from a daughter, referring to the controlling behavior of her brother:

> He became very controlling and always wanted to stick his nose into mom's financial stuff, like she's not capable of doing it herself…He thinks he has to take control or he's the authority over everyone else…And no matter how many of us say to him "you know, you're not the executor until she dies. There's nothing that you should have to be controlling over and concerned."…Mom gets frustrated…He does things behind our back…I work at the bank, so he came there while I was on vacation and asked for a copy of her bank statement…Go and ask mom permission…there's no reason for him to do this kind of stuff.

An additional example represents how a patient's efforts to maintain control can contribute to conflict, in this case conflict between the patient and her primary caregiver:

> When she was in the nursing home and was going to come home again I told my mom "let's bring the bed from upstairs down and put it in there."…my husband and I were…getting the bed from upstairs down and she looked and she says, "you bring that whole damn thing down?" I says, "yeah, I bring the whole damn thing down."…And then we just kept on working and she says, "o.k. get me in the chair" and so [my husband] put her in the other chair and then she was fine…She still wants to have control…she does have control but she still wants to…feel like she's in charge.

One caregiver discussed her own efforts to control the situation, after unsuccessfully

attempting to get input and assistance from siblings:

> My theory became, I got on the train, began to drive it, get in my way, I'll cut you off at the knees. I stopped asking everybody. I just did it and I didn't care. I have the power of attorney…I'm done with everybody. If they want to know they can call me. I'm done calling.

Communication constraints refer to family inability to effectively communicate about death and dying and/or the patient's needs and health status. It may involve distanced family members not being connected to gain information, limited communication skills on the part of one or more family members, and information gatekeeping. The following example from a hospice professional reflects how communication constraints can fuel conflict:

> …mom's the hub, because she's the patient, and there might be four or five kids. Mom had an individual relationship with each one of those kids and the other kid doesn't necessarily know what mom communicated to the brother or sister. The brother or sister may report that accurately or they may not. The siblings may all be banding together in little tribes…and then reintroducing ideas back to mom. And then mom's filtering this out with other siblings. There a lot of communication that never gets to the whole group.

A number of caregivers shared example of communication constraints as contributors to family conflict, as illustrated in this example of a caregiver discussing communication dynamics among siblings:

> So I call my family. Now there's seven of us [siblings]. I have to call every one…"There's a meeting here, here, here [to look at group homes]. If you want to be there, that's fine. If you don't want to be, that's fine too. It's up to you"…Well they come and see and you sit there and you tell them what's going on…they won't say nothing, but as soon as the doors close, that's when the conversation, and she [sister] won't say it right then. She'll go to my older sisters.

This caregiver shared how her significant other's attempts to make his wishes known to

his daughters were blocked:

> He tells the girls that "I don't know how long I got…I want you to know what that I want to have this church…and I don't want the undertaker in [nearby town]…I want the one in [a different town]." And, "Oh, no, no, no, no, don't talk about that. Don't talk about that." And I said, "Mary [patient's daughter]…we need to talk about it."…I try to tell the girls…"we should make some plans here."…"Oh, we'll cross that bridge when we come to it."

Another daughter discussed the limited communication between herself and her brother:

> It's probably my problem that we do have this much communication, and I don't want it to be none, so I'm not going to ask him about how he's feeling. We don't talk about feelings…I don't ask him how he's feeling and then in turn he doesn't have to ask me how I'm feeling, which means he doesn't have to be concerned about me…I'll talk to him about politics. I'll talk to him about religion, but how he's feeling, no that's too personal.

Efforts to seek resolution involve someone in the family having regrets and attempting to seek forgiveness, solve problems from the past, and/or repair previously damaged relationships. The following excerpt from a hospice professional illustrates how historical relationship patterns can be an important contextual element for understanding family conflict. This is an example of a patient who attempted to seek resolution of a previously damaged relationship with the help of the hospice social worker, only to have that attempt further fuel conflict:

> We were told there was a falling out years ago…This gentleman just…really wanted to reconnect with this daughter. We talked about many different ways. Finally he just said, "I can't call her. Will you just call her? Just call her for me. And ask if she'll come to me." So, I said, "OK, I'll make one call and see how she feels about it." Made the one call and the daughter said, "don't think I can do it. Yeah, just can't do it." And we left it at that…A couple of days later I get a call back from her, crying, upset, emotionally upset saying, "You need to know that I was sexually abused by my father repeatedly when I was a child." So did a lot of calls with her, and engaging her into her counselor again, not realizing that that opened up a whole nother emotion for her… I did a lot of talking with her saying,

> "You know, is this – this is an opportunity. Do you need to have resolution for yourself, to see this man again, or are you done?" And she did go back to her own counselor. She did her own resolution. She chose not to see him again. And I talked with him and said…"You need to know that she's chosen not to come back, and you're going to need to die knowing that."

One daughter shared how her father's attempts to seek resolution with her dying mother years after a messy divorce contributed to conflict:"

> When my mom was first diagnosed and he wanted to make his peace with her, after conversing with him, one of my younger siblings found out that what he wants to do is go to her and say, "I forgive you."…He wanted to go and see her so that she could beg for his forgiveness…my sisters, the ones who had the authority to do so, had said, "he is not allowed to visit her," because it would not do her any good…I do get to the point where I thought she was in really bad shape and I called them and said, "o.k. a lot of time has passed. I would really hate to see mom pass away and dad not be able to have his chance to make his peace with her." And they said, "absolutely not…because we've talked with him and he's still of the mind that he's going to go there and she's going to beg his forgiveness."

Family vying for estate &/or position involves family attempts to gain access to finances, material goods, and/or family possessions. It may stem from distrust among family members regarding financial matters and/or simply a desire to acquire resources for themselves. This example provided by a hospice professional illustrates how family resources and demands in terms of money and caregiver health, along with promises made can be important contextual elements for understanding family conflict. In this example of a family member vying for estate or position, a decline in the patient's health status & functioning, along with caregiver exhaustion, lead to conflict between the caregiver and hospice regarding placement of the patient outside of the home:

> …she was the sole caregiver for her mom 24 hours, and she just wore out…she had health problems herself… Mom ended up going to a nursing home and she

> loved Hospice right up until that moment. She will not speak to any of us anymore…she would say straight out "my parents worked too hard for that money to pay for a nursing home. That belongs to me."…you try to tell her, "your parents worked that hard to have money to pay for their care…when they needed it." "That money is for me, they worked too hard and I'm not paying for a nursing home and I'm not paying for this."…she didn't want her mom to go to the nursing home…I think that was something she had promised her mom but couldn't fulfill…But that was very financially motivated too though with her, because she made statements very clearly saying that "my parent's money belongs to me. I'm not going to pay for a nursing home. I'm not going to do this."… what it all boiled down to was she wanted the money.

One caregiver shared how the patient's daughter and son-in-law attempted to gain access to the patient's finances, even as the patient was recovering from surgery:

> [Patient's daughter] is sitting there crying her eyes out. Her husband is sitting there. He's supposed to be at work. Remember they don't have any money…Eight o'clock she says, "he's not waking up. He's not waking up. He's going to die." And I said, "[name], just calm down now." Then she says, "well, he's got to wake up." I says, "why does he have to wake up right this minute? Give him time." "Well, I wanted to know if I can have a hundred dollars." And I says, "[daughter's husband], take her out of here right now."…That's what she was waiting for him to wake up for, money, not his health…and that's why I think she never wanted him to have any surgeries because she was fearful of him dying, but not worried about what the prognosis was if he didn't have surgery.

Another caregiver shared how his sister-in-law's attempts to access the patient's possessions fueled conflict:

> She had been down there and when mom dies she wants this and when mom dies she wants that and we're like, "you've got no say." And my mom is like…"I don't care who get this, but [name] is not getting it." Because she's…starting to act like mom's already gone and we should be splitting things up…she thinks she's going to take over and I'm thinking that's not going to happen. And she thinks her daughter should get this and her daughter should get that…that's just the way they are…more of their tensions and problems is that they're more worried about mom's belongings. It's not that they're arguing over health.

Role expectations & obligations involve expectations family members have of

one another in providing support, assistance, and/or direct care. It may include varying ideas within the family about family roles in the end-of-life situation and a sense of obligation on the part of one or more family members. In the following excerpt, a nurse describes how family members may form role expectations for a family member who has a medical background (which may be perceived as a family resource), and how this in turn, may fuel conflict:

> Sometimes caregivers that have a medical background have the most difficulty, because they have some knowledge, but they don't necessarily have knowledge during the dying process…let's say you work in the birth center or your work in the diabetes clinic. You're not going to necessarily know the signs and symptoms of the dying process. And I think other family members depend on them, and that causes some conflict like, you should be…initiating, calling somebody to get this straightened out, because you're the medical person in the family.

This hospice professional describes a family in which varying expectations about how to support the patient fueled conflict:

> They were over-mothering mom. Some of the family members got it, would take her shopping…leave her alone with her husband. Other family members wanted to be there 24/7, don't take her out and dote on her, and it was driving her nuts. So, we ended up having a family meeting and she point blank said, "you all need to leave me alone so I can do stuff."

Many family caregivers also described the influence care expectations and obligations had on conflict within their families, as in the following excerpt from a spousal caregiver:

> They feel I should be here 24 hours a day and I shouldn't have a life outside and that's where the conflict comes in because I am so used to working and go, go, go…his mom just feels I should be here all the time because when his dad was sick she was with him, but she was retired. It's a little different with me, and I'm 46 years old. I'm still working…she had [an adult daughter] all the time to help with dad…I have no one but me and you try to get that across. "Well, you're his wife." "Well, I'm not a slave."

Another caregiver described how her mother's (the patient's) expectations of her fueled conflict between the two of them:

> I started feeling like her chore girl. I still have difficulty right now walking in her room and feeling like her daughter…she starts asking me to do stuff…She's grateful I can tell, but yet she's become…demanding. She just knows that I'm the one caring for her…When [my brother] came here yesterday…she said, "[participant name] doing a great job. She's still taking care of me and you don't need to worry about helping take care of me"…and I should feel honored, but after a while you start to wear a little thin on that too…She's always become so dependent on me doing it and she kind of shies away from asking anybody else or allowing anybody else to…I am organized…and they know that when you're an organizer, then we'll just put you in charge.

Another caregiver described how her brother's participation in care doesn't meet her expectations for his role, fueling tension:

> He'll do anything that I ask him to do, but volunteering to just come over and just to stay or something like that, no. It's like…"I'll shovel the driveway for you. That way I don't have to come in the house and I don't have to interact… I'll go get the water heater and change the water heater for you" and things like that he's willing to do, but he's lost out on spending time with mom and I think that was what has been bugging me the most all along.

Consequences

Five consequences of family conflict emerged repeatedly in the data. Consequences can take place before and/or after the patient's death.

Restricted/delayed care planning & implementation may occur as decision making regarding such things as equipment in the home or transitions in care setting take longer. In this example provided by hospice staff, the transition of the patient from the hospital to a nursing home took longer than anticipated due to conflict within the family:

> …was only supposed to be there for three days and he ended up being there for a week and a half to two weeks…She was an ex-wife, they'd been divorced for

> quite some time but she wanted complete control over finance, guardianship, she wanted everything. The son said that she was evil and then the father said his son was a con-man, so the mother said that she had to get a restraining order on the son. The son said he got a restraining order on the mother. She wants the car. It was a big mess. And it came into wishes for end of life because he wanted to go to King and the son wanted him to go home with him but she doesn't want him to go home with him. So finances, estate all of that came into play… I think he eventually did get into King but it was quite some time before he got there.

In an example provided by a caregiver, the patient's move to a nursing home closer to home was delayed due to family conflict and the daughter's perceived mismanagement of the patient's money:

> …right now I don't know if I can move him, because nothing has been paid since last year in September. He's that far behind…what I wrote down for what was in his account when he went there and never spent anything is not there now. So somebody had to have used all those accounts and it wasn't me…I should have taken care of it, but he always said he could handle his own finances. Well, then after he couldn't, I said, "Mary [patient's daughter], you can handle that. All you got to do is call the Social Security and make sure that this checking account gets switched over to the health care center."…but she procrastinated like everything else.

Patient wishes &/or quality of care jeopardized may involve patient not being able to live/die in location of choice, multiple transitions in care setting disrupting patient care, and the patient simply not receiving particularly loving care from family members as indicated in this example:

> …the wife who's the caregiver with the alcoholic husband, I think the consequences for him, was that he may have gotten care, but I don't know that it was very loving care. I think his wife just did what she had to do and…I can't imagine what she said to him when they were just alone, how blunt she might have been with her comments. I can just imagine sometimes that she might of said, "you did this to yourself…you get what you deserve."…I can kind of picture her saying that. So, it's kind of sad for him at the end of his life…because it's like you reap what you sew, certainly in his case. He just didn't get a lot of loving care at the end probably. You know care from the heart and that…peaceful loving

death…

No clear examples of this theme emerged from the caregiver interviews. This may be due to the timing of the interviews, though, in that caregivers had not yet witnessed how the conflict would ultimately unfold in their families. It also seems logical that caregivers tended to focus more on direct, practical consequences for themselves and less on quality of care issues than hospice professionals did. Thus, the researcher felt this theme had solid enough support for inclusion in the model based on the extent to which it was described by hospice professionals.

Increased patient, family, &/or team distress may include increased stress; guilt feelings; diminished confidence on the part of the caregiver; relationship strain; and psychological or physical health issues. Stress may relate to the conflict itself, patient or family demands/needs, balancing life responsibilities, lack of help/attention, and/or trying to protect the patient from the conflict. This example illustrates how family conflict can result in physical health issues for the caregiver:

> …she was right in the middle of that and then she's got to make a decision. She got family pulling her one way and staff pulling her another way, Hospice involved in there and this poor woman had to make these decisions. She's trying to make the best decisions...that was so hard on her….She was a diabetic and she ended up, by the time her aunt died she was having a lot difficulty with her diabetes… ended up hospitalized because of the blood sugars and stuff and…I think because a lot of the stress.

Family caregivers shared a number of examples of how family conflict has resulted in increased distress for themselves, the patient, or another family member. They did not share any examples of increased team distress, as that was understandably not a focus for

them, and focused mainly on the consequences for themselves as primary caregivers. The following examples illustrate the depth of distress the can result from family conflict:

> I've had some physical issues. I've had more migraines in the last eighteen months than I have had in the last three or four years before that. I do not sleep much or well, and that's affecting my work in that sometimes it's really hard to stay awake during the day…I have very little patience anymore. I pretty much cry at the drop of a hat.
>
> My blood pressure is going up…I felt overwhelmed and because I'm also the treasurer of our church…plus my oldest grandson is autistic so I kind of like to help out with him…and I work out of town and we have a blended family. Blended families always take a little more time too…I just got over tired, run down and I got to the point where "I can't do this God. I don't feel worthy"…because I can't do one thing good enough…because I have so many things going on.
>
> I actually felt like my blood pressure probably raised…I've never had that problem, but there was a tightness in the chest almost like there was a band around the head…anxious, my sleep was disrupted. Mentally, I'm apprehensive about the future because I know that confrontation is still going to be there. It's unresolved.
>
> I'm a little bit snippy at my husband these days. I am stressed out to the max because I'm trying to do funeral arrangements, make sure she has enough money to stay at the House of Dove [a hospice group home]…make sure she gets what she needs, try to remember everything that needs to be remembered…my memory isn't as good…so I got lists and things all over the place, trying to make sure that I don't go down the tubes health-wise…I'm an insomniac to begin with, so I'm not sleeping at night, going "o.k…did I miss something? What do I need to do tomorrow?"
>
> It's very frustrating, it's very angering to me that I'm not asking her [sister] to take the reigns like I have but to just offer some support…because just the amount of doctor appointments, the amount of phone calls, and that whole process is just overwhelming and it's very tiresome…you suffer emotionally, your work suffers, it becomes very draining and you start to become bitter at everybody around you, and you get tired of the phone calls and so she's the one who probably frustrates me the most.

Severed family relationships may occur as a result of family conflict. In this

example provided by hospice staff, family members severed ties with each other as a result of conflict regarding end-of-life care:

> …from what we heard from the wife, the widow, is that they have not spoken to her since, I mean this family conflict has never resolved…and this was several months ago…the family is completely split apart…two of the children and their families are still very supportive of the mom and the other two boys and their families have not spoken to any of their other family member since their dad's death…It's another thing of as far as resolution of conflict I don't know if that will ever happen with this particular family…And it was just different views on end of life care.

Family caregivers also provided examples of relationships within the family being severed due to family conflict, as in the following excerpts:

> I've gotten to the point now where it's like, if they're [siblings] there, I don't go there because they will argue in front of mother, and I won't do that.

> …my older sister…chooses not to be involved in my mother's care. In fact, she doesn't talk to me at all…we used to talk almost every day on the phone, but she has no contact with me now…it's been ever since we got mom on hospice. She hasn't talked to use at all since that meeting, didn't talk to me at all that day.

> I will not call her [sister]. I cannot call her. I am done. I have tried to pull her back in so many times on behalf of mom and I can't take the beating anymore emotionally cause it hurts. It hurts for mom. It hurts me that it hurts mom so much…When she dies…I'm done…I have so much cut my line with my sister…when mom dies I said she better watch the obituaries, because I'm angry really deep down inside at her…and that's why I don't want to call her…I have shut the middle sister out…I have cut the cord.

> They [siblings] no longer speak to us, which is sad because we always got along really well before that…they were strong in that she needs the nursing home, and we were opposed to it…and now we're good with what's going on, and I think they're happy with this, but now the rift is, you know, it's too late…I've tried to talk to Linda [sister-in-law] and she's literally told me I can kiss her butt…I called to apologize and she said, "one apology doesn't do it" and that was it…I don't think we will ever heal the wound…I don't think she will forgive and…I'm not sure I can trust her after some of the things she said about me…Once grandma is gone, I doubt very much whether all of us will ever get together.

Diminished support for patient &/or caregiver involves situations in which the patient and/or caregiver are not supported by others in the family before and/or after the death. In this example, conflict between the patient and her daughter resulted in the daughter not spending as much time with the patient:

> The patient, she wasn't accepting of her situation and kind of started yelling… from what I've seen she was kind of pushing her daughter away. You know her daughter wants to be there, but, she just, kind of up to the point where she can't take her mother anymore. Because of that she doesn't want to visit as much now. And that particular situation anyway, she's kind of pushing the family away.

Family caregivers also provided examples of how family conflict resulted in diminished support for them as caregivers and/or for the patient. In this example, the caregiver discusses how conflict between the patient and others in the family resulted in family not assisting as much as they could:

> My mom has always been very hard on my sister, forever, so when I ask my sister to help out, she's reluctant, and I don't blame her. But then I try to tell her… "you're just making it harder on me."…I always ask her "what time slot do you want?" and a lot of times, there's four different time slots per day, a lot of times I'll have three…I get frustrated because she's not helping as much, but then it's like I understand because…why would you want to go there and just keep getting shut down…She's got grandkids in the area…but then again she's not always real nice when they do come over.

Responses to Conflict (Hospice Professional Perspectives)

Hospice professionals and family caregivers understandably discussed responses to conflict differently, each according to their own perspectives (family caregiver perspectives will be discussed separately, as they are not included as part of the explanatory matrix). One hospice professional noted that:

> It seems that families that are in conflict at the end-of-life come to the top. They are the families that nurses are having the most concerns about, they're having questions about. They're getting called there frequently. They're the ones that are going to come to a social worker's attention because they're kind of the problem-children…usually a family conflict has been long growing. It is not a new problem, but we need to be able to work within that system…

On that note, three main categories of professional approaches to responding to family conflict emerged from the focus group data.

The first approach, *preventative efforts*, was the least commonly occurring approach. Even with a specific question about prevention during the focus group sessions, only five examples were given by staff. Examples involved the strategies of designating a family spokesperson, utilizing communication books, providing end-of-life education, and facilitating family meetings.

A second approach that seemed to be rather common was a more *"hands off"* approach and took place when staff did not see the conflict as amenable to change and/or within the parameters of their role as professionals. Staff discussed approaches that are not really "interventions," but things that they do and/or ways of thinking that help them manage conflict. They seem to think that in some instances families have to work things out for themselves and that much of the family conflict has nothing to do with hospice. Staff discussed examples of avoiding involvement in conflict and of maintaining a neutral stance. Staff also discussed the use of team as a buffer and support in working with families in conflict.

The third approach, active interventions, was the most common, and this approach is reflected in the visual matrix under moderating processes. A moderator is a variable

that affects the direction and/or strength of the relationship between an independent or predictor variable and a dependent or criterion variable; it is a third variable that affects the zero order correlation between two other variables (Baron & Kenny, 1986). As such, *active moderating processes* refer to actions that deal with the relationship between conflict and its consequences and serve to lessen the effect of conflict. They reflect deliberate efforts by the hospice staff to affect change within a family that is experiencing conflict. These efforts may aim to diffuse the conflict itself, address one of the contributing factors to the conflict, or mitigate one the consequences of family conflict. It is clear that the team feels that hospice cannot force family change and that some family conflict is more amenable to change than others. Staff is more likely to use these moderating processes when they feel that conflict is amenable to change. Hospice staff may never know if interventions are successful due to limited time spent with family. Some excerpts suggested success in diffusing conflict or lessening consequences for the moment and others did not. Staff spoke of interventions that started with the admission process and continued through bereavement, as conflict can be present at any of these points. This study focused on conflict "at the end of life" so bereavement was not included, though several examples of post-death family intervention were given. Staff suggested that some conflict may be resolved after the death. Four primary approaches manifested in the data, each containing a number of sub-themes or more specific interventions.

Approaches aimed at diffusing conflict involve attempts by staff to actually

lessen/resolve family conflict. Specific approaches include encouraging family to set conflict aside to deal with the present situation and to focus on patient needs; helping family members problem solve how to deal with the conflict; providing supportive counseling in an attempt to diffuse heightened emotions; reframing family member behaviors in an effort to help family members "see the other side;" and encouraging family members to "share the care." In this excerpt, a staff member discusses how supportive counseling and refocusing serves to diffuse conflict:

> …listening, that's a big part of it…they just need to talk about it, because they've talked about this for years to their other family members or their friends and those people are sick of hearing about it…So it's just a new person, new ears to let them vent to…It's not that they are automatically asking for us to fix it for them, they just want to get it off their chest and vent all of that…talking with them and focusing on "what do you want to see change, even if it's one little piece of that…you're not going to be able to change that person, what can you let go, what can you focus on in changing yourself, if that's just working on forgiveness."

In this example, a social worker attempts to diffuse conflict by reframing the caregiver's behaviors for the patient to help him understand her perspective:

> …his wife was the caregiver…I could see the pattern, the communication pattern. There was this bickering all the time back and forth. She was trying to take care of him. She was a very, very nurturing woman. He didn't want her taking care of him like that. He was still the man. He was going to be mowing the lawn and doing his thing. But this one particular visit we had was really interesting…he could be nasty to her at times and she was extremely sensitive anyway and he said something to her. I don't even remember what it was anymore, but she left the room crying. And I stayed at the table there and he sat there and he kind of was like "hmm," and all I had to do was really follow up on his lead was about well what's the big deal with her, and I just said to him, "well you know she's really, just trying so hard to take care of you out of love and I know it's difficult for you to accept that. Obviously she feels, very, very badly for what you said to her."…The next visit I had, [name of spouse] says to me, "I don't know what you said to [name of patient], but boy he's a different person to me! He treats me so well now."… and I said to him, "[name of patient], you're very lucky to have

> [name of spouse] so that you can be here at home, where you want to be" and by golly I think that was really it, cause he realized…I should be more respectful to her, because with out her, I wouldn't be where I am…But I felt like that family just came together so beautifully.

Approaches aimed at aligning perceptions of health status, needs, and preferences involve staff efforts to help family members reach an agreement/ mutual understanding regarding the patient's health, needs, care, and wishes. These approaches tend to be used when the present conflict is fueled by incongruent perceptions. The primary intervention here is to provide end-of-life education (i.e. hydration/dehydration, medication use) to "get everyone on the same page." Another intervention is to validate the patient's wishes in an attempt to align the family with the patient's wishes when they are not congruent. The following example illustrates how incongruent perceptions can fuel conflict and how the team might respond by use of education:

> …one family member did not want to give the medication because she felt that it was going to…make her too sleepy….And then other family members wanted the medication given…it was just disagreement between them about what to give and when to give it…then we have to go in and kind of explain why we want to give the med to each family member and try and bring that together so that there's an understanding…Eventually I think, in this situation it came to the point where the family agreed that yes, she needs the medication so that she's not restless. And they could see that she was just more comfortable with the pain medication…when you can intervene…to get everybody back, cohesive….I think just the education that we had given them of well this is why we are giving it. Or why we want you to give it….Giving information, educating the family.

This example illustrates one worker's attempt to align perceptions through validation of patient wishes,

> I always pull it back to the patient and what they want. I think that's so important to be able to do that. Because a lot of times, patients want something entirely different than what their family wants. And if you validate that that's ok, so you

> have to kind of facilitate that…because sometimes patients, unless they get the ok, they will do what a family member wants them to do because they want to save the peace too. So it's kind of a challenge to try to validate what that patient wants. And help them be ok asking for that.

Approaches aimed at enhancing communication are used when the present conflict is fueled by a communication constraint. Specific interventions include facilitating discussion of end-of-life issues and decisions that need to be made (i.e. caregiving, planning for the future) and encouraging or facilitating communication with distanced family members, as in this excerpt:

> A lot of times we see it not as an obvious conflict, but as these old issues that you know, "Oh, well, we're not going to call them"..of not reaching out to family members at the end of life phase…there's resistance to communicating or allowing visits…"Oh, haven't talked to that person for 20 years, so why would I call them now?" But we always try to encourage it. "Well maybe you should just call and offer…Put the offer out there and then it's up to them if they come to see the patient or not." A lot of times it's expressed that way as just that break down in relationship or break down in communication. And our experience tells us that the more relationships that are resolved and comfortable, then the more peaceful the passing will be…I think it helps too with the grieving process after the death, the more relationships that can be rebuilt, the more peaceful the grieving process.

In an additional example, efforts to enhance communication helped a family with a history of conflict and a daughter living at a distance who felt a need to be in control:

> …we have kind of gotten somewhere with that family in doing care conferences and bringing her in and laying some ground work as far as how we're going to communicate…just involving her more, inviting her to physically be there and hear what's going on and see what's going on, and for her to kind of witness us making those communications to the husband…it's gotten better in recent months. So we do a lot of emailing and, and a lot of phone calls.

Approaches aimed at mitigating the distress that results from conflict tend to be used when the conflict itself is not amenable to change. Staff aims to decrease distress by

increasing hospice support (i.e. respite, more visits, volunteers); providing supportive counseling (i.e. listening, validating, allowing to vent); connecting the family to resources outside of hospice (i.e. additional counseling services); and normalizing family conflict. One social worker shared the following approach to mitigating distress by validating feelings and normalizing family conflict:

> Just validating their feelings a lot a time I think allows them to get a lot out …"oh we had a bad night…he only slept for a half hour last night, he looks like he's in pain. I can't tell what to do, then this happened" and just looking at them and saying, "Oh you must be so tired and that must have been such a hard night for you" and just having them go, "Oh, yeah it was!" and just…validating those feelings that, it's ok to be frustrated. It's ok to be angry. It's ok to be tired and crabby right now. This is ok that you feel that way. A lot of times people feel a lot of guilt for getting angry at the patient. "Well, they're dying and I'm mad at them." "Well didn't you get mad at them ten years ago?" "Yeah." "Well, it's ok to be mad at them now."…it's still your husband or it's still your wife…so giving them that permission to maintain the same relationship they've always had and to feel those feelings. That seems to help people a lot actually.

In another example, increased visits and supportive counseling were used in a situation in which the person who was dying had abused his children, physically, sexually, emotionally, and verbally:

> …They deal with these issues of "I feel guilty because I wanted him to die and now he's dying."…they'd feel strong one day and they'd want to be there and do everything they could and then all of a sudden then the next day it would be like I don't want anything to do with this. I can't handle it anymore. And that's where a team approach is just huge. Because we had social workers in there daily and close contact with the family….really try to have only a couple of nurses go in that the family could learn to trust. Build trust with certain team members because trust was an issue for them. Social work, chaplain, spiritual, whatever they thought they needed. Whatever we could bring out of them in conversation as to what was lacking, what they were feeling. Or just giving them that opportunity to express it, that internal conflict, and being accepting of that…and showing a very non judgmental attitude that what he did was wrong but were still are going to care for your dad…We accept you for who you are…A lot of kind of lifting them

up.

Facilitation of family meetings is a key intervention for hospice staff and tends to fulfill more than one of the above aims simultaneously. Family meetings serve to unite and involve family in the planning process; ensure that family members receive the same education and information regarding the patient's health and needs; discuss how communication will take place within the family and with hospice; provide an opportunity for family members to share concerns, express needs, ask questions, and give input; and allow family to develop a relationship with the hospice team. In some instances one family meeting takes place, while in others, multiple meetings are needed. Family meetings may be facilitated by just one team member, but preferably are multidisciplinary. One staff member shared how family conflict was lessened through the use of a family meeting:

> …the only conflict was that they were over mothering mom. Some of the family members got it, would take her shopping, leave her alone with her husband. Other family members wanted to be there 24/7, don't take her out, and dote on her, and it was driving her nuts. So we ended up having a family meeting and she point blank said "you all need to leave me alone so I can do stuff."…they were all very receptive of it. And we were just there facilitating it saying "when she's having a good day and wants to go out and do some shopping"…So went around, "so what kind of things would you like to do with your mom while she's feeling good?"

Another staff member described the process and goals of a family meeting in the following way:

> …to kind of get everybody in one place, hearing the same information, all at one time and being able to ask questions in front of each other…If we feel like they're not communicating well or they have different understandings of things…the social workers will invite everyone that we're aware of. There's no required attendance or anything, we just invite…it's just an opportunity for everyone to sit

> in one place. Usually the first thing we do is to offer them to ask questions. So that we know what they want to know and what their goal is out of the meeting. And then we just try to offer information and teaching, so that everyone hears the same thing. And then we can kind of identify who has trouble with accepting what part of it…try and make it relaxed and open so that people feel comfortable saying what's on their mind…And then also usually it helps to kind of get everybody to agree on a plan. You know, what do we want to do? How are we going to do it? Who's going to do what? So we kind of put that right on the table in front of everyone, so that this is the plan we agree on. This is how we're going to proceed.

Another staff member discussed the importance of family meetings in this way:

> When you have a family that's identified that as having conflict, that's when you need to go in and you need to have a family meeting. You need to have all the parties in one place and you need to have the same education, the same information going to each one of them… We all know that people process differently, but I think its our responsibility as hospice professionals is to make sure that we are giving all of them the same information so that we can go back upon that at another visit, another time and say, "Remember when we discussed this" and they've all heard the same thing. So communication, communication, communication. Education, education, education. And I know that many people would like to think one meeting is enough and everything's resolved, but what you see in a family conflict is one meeting that's going to lead to another meeting that may need to lead to another meeting. These are families are going to take a lot more time, a lot more patience, and a lot more education.

In discussing approaches to responding to conflict, the importance of the interdisciplinary team emerged as an overriding theme. Staff discussed relying on their team for a number of purposes, utilizing them in patient homes, in staff meetings, and behind-the-scenes in their day to day work. This example illustrates the importance of team to share the responsibility of working with families in conflict:

> Sometimes too we try to take turns, if you don't want to get too drained by a family and sometimes, having somebody else go in there and visit, kind of divide it up, just kind of gets the family not to rely on one person or to drain them dry. I mean, basically, that's what they can do. They can just suck the life out of you.

In this excerpt, a staff member discusses the use of team for expertise in various areas of need:

> …use my team members, my social worker, in helping because I may know the medical part of it, but I do not know the psychosocial. I do not know the spiritual. I do not know the grief. So this is where I feel as though…it's not what you know. It's who you know and how to get your questions or your concerns answered. And I feel the hospice team working together as a team, with the family is very helpful in resolving the conflict that may come about, using their expertise in their specific field.

A staff member discussed team as important for maintaining a united front in working with families in conflict in this excerpt:

> …as a team, that you have really good communication, so the family doesn't have the opportunity to use one person against the other...Cause if you both say the same thing, because you've talked about it, and you're aware of what was done during that other person's visit, then it's a lot easier when you go in the next time…Because you do get kind of people who are manipulative, you have to safe guard against that.

Another staff person related how team is used to maintain professional objectivity in the face of conflict:

> I think sometimes the challenge for us as a team is…to keep the team together to keep the team focused and objective. And I think now that we have partnered nurses, that's really made a big difference. So you don't have someone feeling so overwhelmed and so entrenched in that family that it's hard to maintain objectivity.

Responses to Conflict (Family Caregiver Perspectives)

Most caregivers noted that there was nothing hospice could do to fix the conflict or change the people involved in the conflict. In fact, approximately 80% of participants said that the conflict was not amenable to change, and that they did not expect intervention from hospice staff. In some instances, caregivers admitted that hospice was

not even aware of the conflict, either because family had deliberately chosen not to share it and/or they did not perceive having an opportunity to discuss it with staff. The following excerpts illustrate family caregivers' perception of their conflict not being amenable to intervention by hospice staff:

> I don't think hospice would be able to make a difference there. I mean that's just the way they are…none of their arguments really ever come about mom's well being. It's more of the personal belongings and that's not anything hospice is going to be able to beat any sense into their head.

> I really don't know what they [hospice] could do at this point, because I think my family kind of said "well Jane and Linda are making all the decisions because they're power of health care and we really don't have any say into it"…I really think they have to come to terms with it more and open themselves up and be available, like we could set up another meeting but I couldn't guarantee that they'd all show up.

> I told them [hospice] don't worry about it. That's what I told them, because you're not going to change Jackie. You're not going to change Ronny…We really haven't had any intervention in family issues, and when I think about it, I really don't know if there's anything anybody can do…

When asked directly if hospice has done anything helpful to address the family conflict, caregivers were able to cite a number of examples of staff involvement. Most examples, though, did not illustrate attempts by staff to address the conflict itself, but rather to address the consequences of conflict for the caregiver, strategies to care for the caregiver in light of the family conflict. Also, examples of intervention were rather limited, indicating somewhat of a mismatch between what hospice staff say they do and what caregivers perceive. This caregiver discussed how useful respite and sharing care provision has been in terms of her own stress relief in light of not having much support from her family:

> We haven't had any intervention that way, but the biggest thing is having more people interacting with my mom…and now there is a hospice volunteer who comes in two evenings a week and just having that time has been so nice because it gives me a chance to even if it's just to run out and get groceries…[Having hospice involved] gives me the chance to kind of step back and say, "o.k., I can relax because I know there is somebody there specifically for her, specifically to meet her needs."

This caregiver discussed the usefulness of hospice allowing her to vent and process her situation in alleviating the distress of caring for her father in the context of family dysfunction:

> They are very good at talking, listening…and I think sometimes that they come as much for me as they do for him honestly because if I want to talk or say anything, they're never in a hurry and I really, really appreciate that because just talking for maybe 5 or 10 minutes, just venting, just getting it out, helps so much and then it's over with, you go on to something else, get away from that stumbling block.

Several family-focused strategies were cited. One caregiver discussed how having hospice involved served as an aid to decision-making within the family:

> It [getting hospice involved] was really a relief for [participant's sister] and I because we were bombarded with all these "what are you going to do now, [participant's name]? What are you going to do now, [sister's name]?" but we [remaining siblings] don't want to be part of it…So, who's going to make the decision?

A couple of caregivers noted strategies for addressing problems with communication that arose due to conflict, particularly the usefulness of hospice in facilitating information exchange among family:

> It seems like things are much more interactive and evenly distributed as far as the exchange of information…between the hospice organization and the whole family.

> We've got a guest book in her room…and I write notes about my visits or what we talked about, what our day was like…The hospice volunteer has been writing

> in there…The hospice nurse will write in there, the social worker, the chaplain, and that's been fantastic to have somebody besides me writing in it and my siblings will, when they do come to visit…I know that the hospice people have read the previous entries, and that's been, "o.k. great. I feel like my experiences are validated."
>
> That's why I wanted hospice involved…that way he [brother] doesn't have to go through me. That way he doesn't have to hear about me…you guys can be the experts. He can have some power back, and I wanted him to have that power, if it made him feel better.

Of significance is that caregivers also commented on the usefulness of family meetings:

> They [siblings] were all there the first day. When the social worker and the nurse came and we did the interview and the admissions assessment…they all showed up…to hear all of the information, to ask their questions. It was a good interaction I think with everybody because they weren't afraid to ask.
>
> My brother…did say, "you know, I think that was a beneficial meeting" and most of the care providers said, "…I'm glad we had that meeting, because we got some of our questions answered." And I said, "maybe we'll have to have another meeting."…I think it opened up a few people's ears.

Based on the limited examples of intervention provided, it seems that family caregivers did not perceive hospice to have an active role in directly addressing conflict and/or alleviating its effects. One caregiver went so far as to express her frustration at the lack of attention to family needs:

> You read the literature and it tells you know they help the family through it all and no one's offered to help me yet…I feel sometimes confused as to what I am supposed to be responsible for…no one really sat down to explain…no one's offered to speak with me either, and the books say, the literature says there is someone there to help you…but right now, I'm a bit disappointed in them and the system to be honest.

Family caregivers also provided suggestions for intervention, identifying things that they felt would be useful in addressing family conflict that had not been fully

provided to them. One area of need identified was additional attention to the caregiver to provide emotional support, listen, process on a regular basis, and make suggestions on how to better approach family issues. One caregiver shared her ideas regarding how hospice might better attend to her needs:

> If I could make a wish list, one of the things on there would be to have a regular meeting with someone just to say, "how are you doing?" because I'm not necessarily the best person in the world at taking care of myself…right now I'm focused on taking care of my mom and just getting through every day…that would be a nice nurturing thing that maybe wouldn't necessarily take much other than say every Thursday at four o'clock let's sit down and talk about how are you doing this week, even for only fifteen minutes…something on a regularly scheduled basis…to me it would be almost on the level of I've got a doctor's appointment.

Another area of need identified by caregivers was that of reaching out to other family members who may be distanced and/or struggling with the patient's condition. The following caregivers shared their sense of how this might be helpful:

> …my older brother is right now feeling out of control…I feel that if he talks to them or they talk to him…and ask him how he feels about this and is there something, that he will gain power back…they will listen to them, and "no, your sister pretty much said because we know what we're doing, we're in charge, but we are talking to you about this so we want to know how you feel about it." I'm hoping it will empower him that he feels a little better about this…if he felt he had a little more power over it he would feel better in the end. When the end came, that he said, "yeah, I told them to put the blinds this way and it worked." Something to grab on to…to say "I did this and I was important and I helped."

> Nobody has reached out to her and…we don't understand why…They could have reached out to a sibling who is disengaged…could it have given us a better understanding, because she won't talk to us because it's very much, the conversation always feels very defensive when you do call.

Family caregivers also noted the need for increased intervention to facilitate communication, requesting direct participation and feedback from other family members,

providing updates on the patient's status, and being a "go between" between family members who are not able to openly communicate. The following examples from caregivers illustrate these suggestions:

> How could somebody in hospice help? Gathering all the emails that they can and just making up a little…third party type thing…just fire off an email to everybody…after a visit by one of the nurses, they put a couple of lines about what they see, might be very very helpful…maybe not so much a clearinghouse for all of us emailing each other, but this week she was alert and talkative and we noticed this.

> He [brother] can be involved but not through me…He can talk to them whenever he wants. He can call them up ahead of time and say, "is she there?"…and if they need to be a go between, they call me up and they say, "your brother's up here, don't come up here"…whatever that would help him feel better…the gift I could give my brothers and hospice is able to help with that, to give them no regrets, that would make my life just so much nicer, because they are my brothers no matter what kind of a pain they are.

> I'm not a doctor. I'm not a nurse. But I want to make sure that they have the information…that's where a third party…somebody whose had a little more experience maybe with the dying process, somebody who's in a health care role, whether it's the social worker or the nurses that "you know, I think things are getting…" And when I start reading through some of the literature that I have on the dying process from the hospice people…it's like you see these things happening and it's just all part of the process. That kind of information, having that, I've been the one giving it out…Maybe being more actively involved with those people. I know they are a little further away…being able to do that kind of information exchange would probably be more helpful to me.

Family caregivers also suggested the need for regular, and more highly recommended, family meetings, as in the following excerpts:

> [Hospice could have] brought the family together, or said, "we have to have all family members there for the hospice meeting, in order for it to move forward." Could there have been a more forceful or it's highly recommended, would I have asked hospice to call my middle sister? Yes, I would have. I don't know if it would have had more impact, but they would have gotten a feel from her as to pulling me out because I am so emotionally attached to it.

> Ongoing family meetings would probably be a good idea, because then people talk, and sometimes you need a mediator to bring these things out…I think that a lot of times…people get together and will talk on the surface…but you need someone to start the hard questions, "how do you feel about that? How are you dealing with that?" Someone to dish out those hard questions, because they're difficult to say…I just believe that you need family get togethers, one on one just doesn't help the whole…workings of it.

Finally, two family caregivers identified the need for professional involvement earlier in the disease process to prepare families, whether hospice intervenes earlier or other medical providers assume more responsibility. The following excerpts illustrate this perceived need:

> I needed hospice in the beginning, as soon as she was diagnosed…I know hospice doesn't come on until the last six months, but even if there would be something, where there's someone like me who could just talk to somebody about the process or here's for when we get to this, here's what we will do, because it was just such an unknown of what will hospice do, how will they do it…because I really didn't have anyone emotionally to support me…Even if there could have been a meeting in the beginning saying, "your mother is dying…how or what are your roles going to be"…I feel like that would have been a tool that would have said we'd like to pull all family members together… "here's what hospice will do. Do you have any questions about your mom, things down the road?"…there was so much unknown...this shouldn't be a hurtful time to mother, not to have her three children there together…If there was an initial meeting with family that could help bring everybody to the plate together…you keep hearing the doctor go, "o.k., we're going to sign these papers that mom's incompetent," am I going to have a sibling come out of the woodwork who's going to challenge me?…Why doesn't it come to the table sooner?

> Is there help from the medical standpoint that they could prepare you a little bit more maybe prior to a hospice situation…her doctors, they could have prepared me better.

Conflict Resolution

When asked about potential positive outcomes of conflict, participants mostly

discussed situations in which conflict was resolved. The theme of conflict resolution, though important, did not emerge fully enough to warrant inclusion in the above model, but is worthy of mention here. Examples provided indicated that conflict resolution may occur with or without hospice intervention. Resolution that occurs regardless of hospice involvement may be influenced by the terminal situation itself causing family members to reconsider prior conflicts and forgive; positive coping mechanisms; faith; love and respect for the patient; and the patient taking control to encourage resolution within the family (the patient is often in a position of power to do this). Acceptance of the terminal condition can bring about resolution (either temporary or permanent) of family conflict. Consequences of conflict resolution that emerged in the data included a more peaceful death for the patient, increased family cohesion either short term as families "pull together" to care for their dying relative and/or long term, as relationships are strengthened, enhanced communication and decision-making, increased confidence on the part of the caregiver(s), increased likelihood of the patient dying at home, increased family involvement in care, and a more peaceful grieving process for the family. A hospice professional shared this example of how resolution took place within a family due to the patient's efforts, resulting in improved family relationships and likely less distress:

> There were seven children who bickered with each other pretty constantly about everything around their mother's care, but they all loved and respected their mother who was the patient and she was able to use that to instill in them a way to get along at least through her illness. She was bed bound and we had asked for a family meeting, and I wasn't sure how this was going to play out…thought this looks good on paper but I'm a little fearful of what it's going to turn into. And

> the patient took charge of the whole thing…she was in her bed and she had everybody sitting in a circle around her in chairs, spouses, adult kids, and the whole bit besides her own children and she called them up one by one to sit next to her in her bed and she talked to them loudly enough so that everybody else could hear and she told each person there what she treasured about them and then she asked them individually one by one to be nice to each other basically and to appreciate the differences that they had. It was really wonderful… I think after the death…from what they told me over the phone they were getting along. I'm mean, it wasn't a big happy family forever but they were proud of themselves for having gotten that message from their mother and they could keep it together for her sake, out of respect for her.

The following example provided by a family caregiver illustrates how resolution may naturally take place due to the patient's disease progression and the family's increasing acceptance of impending death, resulting in increased family involvement:

> I wouldn't call it so much disagreements as tension, I guess…[my brother and sister] in the beginning weren't as helpful…the dynamic is starting to change now the closer she gets [closer patient gets to death], which kind of disappoints me because they've missed out on all of this time when she was still able to communicate with them…they weren't spending any time…And that used to irritate the hell out of me…But now, as things are progressing, they're spending a little bit more time.…And then daddy at first was, it was hard for him to accept…"she's just being stubborn…She knows what she's doing." He wouldn't accept it at first. Then when he finally did accept the Alzheimer's, you could literally see a change in him…Before he was accepting to that, I was just… another mom, because the relationship mom and dad had is, he was the husband, she was the wife, she waited on him hand and foot…and at first that's how…he treated me…and so that was a little bit hard at first…he was pretty demanding, and that made it a little bit difficult…After he finally accepted the Alzheimer's, he became more attentive to her, and a little bit more helpful to me. Since we have the diagnosis now of cancer, he's really changed because he realizes now this isn't going to be a long term thing anymore.

CHAPTER 5—DISCUSSION AND IMPLICATIONS

This study offers an explanatory matrix that portrays family conflict as a complex phenomenon influenced by salient contextual variables, conditions, and factors that may contribute to a number of negative outcomes for patients, family members, and professionals. It provides a beginning understanding of approaches utilized by hospice professionals in their work with families experiencing conflict. This study also provides insights into the correlates and predictors of family conflict, allowing for the testing of some elements of the explanatory matrix.

Though family conflict is a significant issue for hospice professionals and family caregivers, it has not been researched sufficiently. Prior research has largely depicted family conflict as a unidimensional construct, limiting our understanding of its complex nature and extent (Clarke, Preston, Raksin, & Bengtson, 1999; Semple, 1992). Efforts to address family needs in palliative care have been hampered by the lack of descriptive data "regarding the composition or dynamics of families who characteristically need the most support" (King & Quill, p. 713, 2006). Further, most studies involving end-of-life caregivers have been retrospective, using interviews with family members after the patient's death. This approach is often taken to avoid interference in end-of-life care and to protect terminally ill individuals and their family members, who might be considered vulnerable during the final months of the patient's life. It does not; however, allow for an accurate depiction of family experiences at the end-of-life, as family caregivers struggle to recall and describe their experiences, thoughts, and emotions and/or as heightened

emotions dissipate over time. This research was not wholly retrospective, but addressed conflict as it was occurring in the end-of-life context. The results provide us with a more accurate, rich picture of family experiences.

This study makes valuable contributions to the end-of-life community. It fills a significant void in the literature by giving attention to two significantly under-addressed issues, end-of-life caregiving and family conflict at the end-of-life. Though an extensive research base related to family caregiving for a number of patient populations exists, little attention has been given to the experiences and needs of family caregivers in end-of-life situations. This study acknowledges that end-of-life care occurs in a family context, going beyond the individualistic assumptions associated with western medicine. This study also extends beyond the typical focus on the adverse mental and emotional consequences of caregiving and reaches into the broader social context. There is general agreement that end-of-life caregivers are at risk for psychological and emotional distress, but little research has attended to other issues and implications.

The social work perspective utilized in this study offers further contributions. Psychosocial and familial issues have not been examined adequately in the aging, medical, and end-of-life fields. Despite renewed energy in the profession to rectify the shortage of social work researchers who can advance knowledge for practice and policy in aging, social workers are underrepresented as investigators in this field. Interest in end-of-life issues is even smaller, representing just a fraction of those individuals focused on aging (Morrow-Howell & Burnette, 2001). Only a small number of social workers

are publishing research and gaining funding for aging and end-of-life research, and though social workers appear to be publishing substantial research on caregiving, little of such research focuses on caregiving at the end-of-life (Morrow-Howell & Burnette, 2001).

This study emerged out of earlier research conducted by Kramer et al. (2006), which examined family conflict from the perspective of interdisciplinary staff caring for low-income elders with advanced chronic disease in their last six months of life in a community-based long-term care program. This study provides strong support for the explanatory matrix developed by Kramer et al. (2006) and built on this previous research in a number of ways. It examined family conflict more in depth, from multiple perspectives, and specifically within the hospice context. Hospice is known for its expertise in providing end-of-life care and for its focus on family as the unit of care, though no research has targeted family conflict in the hospice context. Including both professionals and caregivers in the sample allowed for the exploration of diverse stakeholder perspectives on family conflict and the examination of the extent to which they had congruent ideas about conflict as a problem, its consequences, and potential solutions. This study more closely examined professional approaches to address conflict, serving as a starting point for identifying interventions that can be additionally investigated. Further, the use of both qualitative and quantitative methodologies provided a combination of both rich, descriptive accounts of family conflict and quantitative data supporting some of the themes arising from these accounts. This combination gives us

unique insight into the very personal struggles experienced by some families and also strengthens our confidence in the accuracy of certain components of the explanatory matrix.

Results of the present study will now be reviewed and discussed, along with recommendations for policy and practice. In general, the results suggest that family conflict can be rooted in the family context and/or can result more directly from interactions specific to the end-of-life situation. Conflict only derives meaning within the context of the family system, and families bring many influential background characteristics with them when they enroll in hospice. These characteristics, coupled with conditions that occur for most families facing end-of-life and contributing factors unique to each family, combine to create situations ripe for conflict and consequences that can have significant bearing on the well-being of all involved. Though conflict can be outward or direct, it also often manifests in subtle, underlying ways and is sometimes hidden and/or suppressed by caregivers. It most commonly occurs among members of the family, but can also take place between the patient and one or more family members, or between hospice and one or more family members. Though hospice professionals attempt to address family conflict in many situations, overall their efforts are not well formulated and often go unrecognized by families.

Prevalence of Family Conflict

Though overall levels of family conflict were relatively low in this study (mean score of 1.39, SD = .63, range 1 – 4.5), some form of family conflict at the end-of-life

was reported by over half (57%) of the survey respondents. These figures are higher than those reported in a recent study of family members of persons who died from lung cancer (Kramer et al., 2009) in which 35% reported some type of family conflict (mean score of .38, SD = .76, range = 0-4), but comparable to levels reported in a study of low-income elders in which conflict was present in 55% of the deaths reported in a fully integrated managed care program (Kramer et al., 2006). The higher numbers in this study may be due to data being collected as conflict was occurring (reducing the potential bias involved with retrospective data collection) and/or the inclusion of more items in the family conflict scale to choose from (the 2009 Kramer study used only 4). Regardless, family conflict is a commonly reported occurrence, and conflict need not be severe and/or span multiple domains to be troubling to patients, family members, and professionals.

The Family Context

A key finding of this research is that the family context is a significant factor in understanding family conflict at the end-of-life. During focus groups, hospice professionals cited numerous examples of family conflict that were fueled by aspects of the family context, and all fifteen interview participants shared one or more examples that illustrated its significance for their present situation. The quantitative analysis supported the importance of this part of the conceptual model as well, with a number of elements of the family context significantly correlating with family conflict, explaining a large percentage of the variance in family conflict in the regression analysis, and standing out as significant predictors of family conflict in the final model.

During qualitative analysis, all of the themes proposed by Kramer et al. (2006) were supported, and the new themes of family structure; substance use, abuse, & dependency; advance care planning & promises made; and faith traditions & belief systems emerged from the data as well. With many families facing such challenges in today's society, it is not surprising that these additional themes emerged, demonstrating the complexity of family systems prior to the onset of a terminal illness. Results of the quantitative analysis further validated the role that a history of conflict can play for families faced with terminal illness. Of particular interest is that almost half of the survey respondents reported conflict in their families prior to their family member's diagnosis. The significance of prior conflict in understanding family conflict at the end-of-life has been demonstrated in previous research as well (Kramer et al., 2006; Kramer et al., 2009), though no previous research has captured in such descriptive detail the history of conflict that some families experience that may manifest at the end-of-life.

The quantitative data suggested that longer lengths of caregiving relate to family conflict at the end-of-life. This may suggest a link between caregiver burden and family conflict, as many caregivers provide complex care without the support of other family members, often for long lengths of time. As such, resentments and frustrations may easily surface, as caregivers may become exhausted and overextended. Though a fairly common occurrence (almost 20% of survey respondents), the caregiver having to provide assistance for another family member or friend did not significantly predict conflict.

Previous research has suggested that advance planning can ease tensions for

families, as practical planning and discussions help family members come together in their thinking and preferences and feel more secure with decision-making. This study supported the importance of advance planning as an element of the family context through both the qualitative and quantitative data. Interestingly, the actual completion of a living will or power of attorney for health care did not demonstrate a relationship with family conflict during quantitative analysis, whereas discussions about wishes did. This may suggest that communication about wishes is really the most important, not whether or not a document has been completed. However, Kramer et al. (2009) also detected no relationship between having a power of attorney for health care or a living will, but found that reports of conflict were actually higher in situations in which patients had expressed their end-of-life care wishes. These mixed findings about the relationship between advance planning and family conflict suggest the need for additional research in this area.

The results of this study suggest that family conflict at the end-of-life can span socioeconomic groups, care settings, and relationship types. Though Kramer et al. (2009) found racial differences to be a factor in conflict, the sample in this study was not diverse enough to examine that particular aspect. The survey data did suggest, however, that conflict was higher among female caregivers, younger caregivers, and those with children in the home. Kramer et al. (2009) also found conflict to be higher among younger caregivers. There could be a number of explanations for these findings, one being that women and younger caregivers are more likely to take on multiple roles and responsibilities within and outside of the family, increasing stress and possibly fueling

conflict. Adding children to the equation may further complicate things, not only in terms of increased responsibility, but also because caregivers must decide how to approach the topic of death with the children. It is also possible that conflict is more equal between male and female caregivers but that women are more likely to report conflict when it is occurring and men tend to minimize it.

Families come to the hospice table with a lot of issues already on their plates and as the terminal situation adds even more issues and stressors, difficulties within the family context may resurface and/or exacerbate. Previously damaged relationships, maladaptive coping patterns, differences in belief systems, the strains associated with long lengths of caregiving, and poor communication about end-of-life wishes may place families at risk as they are faced with coordinating care and making decisions regarding their family member. Deeply ingrained family dynamics do not just suddenly change during times of crisis. Hospice professionals are faced with not only conflict that surfaces related to the terminal illness itself, but they regularly encounter that which is deeply rooted in the family system.

Conditions

The qualitative piece of this study supported each theme highlighted in the previous research by Kramer et al. (2006) as being a significant dimension of family conflict that facilitates, blocks, or in some way shapes actions and/or interactions" (Kools, 318). Obviously, the key contribution to the matrix of the present study is the inclusion of "admission into hospice." Focus group and interview data provided many

examples of situations in which the decision to admit to hospice and/or the admission process itself facilitated conflict among the family and/or between the family and hospice. This condition is unique to the hospice context, as admission for many families signifies acknowledgement of the terminal condition, agreement with palliative versus curative care, and a decision to forego any life-sustaining interventions. Professionals should be sensitive to the significance that hospice admission may have for the family.

Only five of the relationships examined between the conditions (i.e. ADLs, IADLs, and coming out of the woodwork) and the contributing factors (i.e. death anxiety, communication constraints, and family asserting control) and family conflict demonstrated significance during correlation analysis, with three being at the trend level. Further, the conditional variables themselves did not make a significant contribution to the regression model. Greater patient ADL needs were found to relate to lower levels of death anxiety. This may suggest that when a patient's physical care needs become more advanced and death approaches, caregivers have less difficulty psychologically or emotionally facing their family member's death, as they are witnessing deterioration and increasing their caregiving. Greater patient IADL needs were found to be related to greater family conflict and greater levels of family asserting control. This may suggest that tensions and control issues arise as families are challenged with managing these practical matters. Coming out of the woodwork positively correlated with family conflict and death anxiety, suggesting that when family members who were previously uninvolved "arrive on the scene" conflict may ensue and caregivers may have a more

difficult time accepting the impending death.

Kramer and colleagues (2009) also examined the relationships between certain conditions and contributing factors and conflict. In contrast to the present study, they found that difficulty accepting the illness was higher among families of patients with more clinical care needs. Similar to the present study, they found physical and psychological symptoms to be associated with family asserting control. Kramer et al. (2009) also found physical and psychological symptoms to be associated with communication constraints and with family conflict itself, whereas the present study resulted in no such finding. Differences in these findings may be due to the population examined and/or differences in how measures were constructed.

It seems that the conditions associated with conflict do not predict conflict in and of themselves. That is, a patient can have high care needs and/or family members can "come out of the woodwork" in high numbers and the family may not experience conflict. It seems rather that **how** family members "come out of the woodwork" may make a difference. If the family context is one consisting of a lot of prior conflict, "coming out of the woodwork" may be a challenge, whereas if the family context is void of conflict and the family generally functions well, "coming out of the woodwork" may be welcomed. It may not be the condition itself or the additional contributing factors, but rather the combination of family context, conditions, and contributing factors that carries power.

Contributing Factors

During qualitative analysis, all but one of the themes resulting from Kramer et al.'s (2006) research was supported. Though instances of "family anger and distrust" emerged from the data, this theme was believed to conceptually overlap with the definition of family conflict used in this study. Thus, it was not included as a contributing factor in this explanatory matrix. Additionally, two new contributing factors emerged from the data, "family vying for estate & position" and "role expectations & obligations," adding to the list of actions or interactions stemming from the conditions that may fuel conflict.

During quantitative analysis, contributing factors uniquely explained 27% of the variance in family conflict, after controlling for family context and conditions, and two of the three contributing factors (i.e. communication constraints and family asserting control) were determined to be significant predictors of family conflict in the final model. Unexpectedly, death anxiety did not relate to family conflict as anticipated. This could be due to the way in which death anxiety was measured in this study. The measure only involved one item examining the extent to which the respondent felt that thinking about their family member's death was difficult for them. The phrasing of this question may not have allowed for an accurate portrayal of the concept of death anxiety. Additionally, it only examined the respondent's anxiety, not the anxiety of other family members. It is possible that death anxiety was an issue within families, but experienced by family members other than the respondent. Death anxiety may have related differently with family conflict if a more accurate measure had been used. Though some of the family

context and condition variables included in the regression equation differed, Kramer et al. (2009) also found communication constraints and family asserting control to be significant predictors of family conflict in the final model. These findings suggest the importance of open communication and shared decision-making in avoiding family discord at the end-of-life.

Consequences

Under the consequences domain, all of the themes generated by Kramer et al. (2006) also emerged in this study, and two new themes of "severed family relationships" and "diminished support" surfaced as well. These findings broaden our understanding of the implications of family conflict on the family system, revealing the temporary and/or permanent damage that can occur. Further, at a time when much assistance and support is typically needed to provide patient care and cope with the impending loss, caregivers are often left relatively isolated as a result of conflict within the family. As one caregiver noted, "caregiver is the worst and hardest job there is…especially then when death is knocking at the back door… it's even harder because that's when you want the family and that's when they seem to be pushing you away." Quantitatively examining the consequences of conflict was beyond the scope of this study.

Preventing Family Conflict

Results of the qualitative analysis revealed that few preventative measures are being used by hospice staff with respect to family conflict. Short lengths of stay in hospice, coupled with large caseloads and significant administrative responsibilities may

make attention to prevention problematic. Families often enter hospice with the patient having one to two weeks to live, and hospice professionals are forced to focus on the most immediate needs. Pre-existing or emerging conflict may fall by the wayside as the team and family focus on the actively dying patient. Despite this challenge, the development of a prevention protocol may prove extremely useful. Warding off family conflict at the end-of-life may result in avoiding the often harsh consequences indicated in the explanatory matrix, which would be no small matter for families and professionals alike.

The strategies discussed by staff in this study might serve as a starting point for designing a prevention protocol that can then be further examined through research. Designating of a family spokesperson and utilizing communication books with each family admitted to hospice may ward off such contributing factors to conflict as communication constraints and family asserting control. Providing basic end-of-life education early in each admission may prevent incongruent perceptions and facilitate acceptance of the impending death. Proactively having family meetings with every newly admitted family may lessen the chance of later conflict by helping family members to voice concerns, coordinate efforts, plan for the future, and learn about hospice and the dying process right from the start. Though implementing such prevention strategies with each and every family may prove to be time consuming, the time, stress, and harm saved by preventing conflict in some families may make it worth the effort.

Ideally, these and other preventative measures should start prior to hospice

involvement, involving others in the medical system, and hospice personnel might collaborate with other professionals to design them. The medical community should consider ways to help families discuss wishes for care earlier in the disease progression, and though completing advance directives is still important, discussions among the family should stem from them. Lengths of stay in hospice are often very short, and although hospice professionals should also encourage and facilitate advance planning, such processes should ideally start earlier on.

Assessing and Addressing Family Conflict

Hospice professionals clearly view family conflict as significant in their work, yet it is not fully, specifically assessed for by multidisciplinary staff. Screening strategies have already been used to identify at-risk families in palliative care for a family focused grief therapy intervention (Kissane et al., 2006), and many hospice programs already conduct multidisciplinary assessments for characteristics such as "bereavement risk" and "depression." Developing a similar protocol for family conflict could prove useful. Having identifiable "red flags" or "risk factors" grounded in research may result in a more objective assessment of the family's context and potential contributing factors. Identifying and acknowledging family conflict from the start of service may help to prepare the team to best work with the family and may help the family to address issues that help them work more effectively together. Others share the suggestion to implement routine screening for family functioning and conflict with similar populations (Lichtenthal & Kissane, 2008; Zabora & Smith, 1991).

A number of factors should be considered when assessing for family conflict in the hospice context. First, the point in the patient's disease trajectory in which hospice enters the picture may influence the extent and nature of conflict observed by the team (i.e. hospice admission just following diagnosis of a fast moving cancer may be different than hospice admission following five years of progressive dementia). Family members may have accepted, for example, that their family has a lot of conflict or may have worked out some family problems if they have already been involved in attending to the patient for many years. Second, assessment should be ongoing, and professionals should avoid making quick judgments of the family's functioning. Building an ongoing understanding of the family system is important with the realization that change may occur over time and that complex family dynamics take time to understand. What appears to be a cohesive, conflict-free family on admission may end up being a family full of conflict and conversely, what appears to be a family full of conflict at admission may end up being a family that ultimately functions very cohesively. Third, it is important to recognize that much of the family history may remain unknown and professionals should never assume to know the full story. Some family conflict arises out of painful experiences, for example, that are not openly discussed within the family or with others. The caregiver in this study who was physically and emotionally abused during childhood by her father, the patient, who also sexually abused others in the family, serves as a striking example of this. Her family history certainly impacted the present situation, yet the hospice team was not aware of it. Though it may have been helpful for

the caregiver to share this information, families should obviously maintain the choice as to the extent of hospice knowledge of, and involvement with their issues.

This study revealed that hospice professionals already have a strong base of intervention ideas to draw from that need to be investigated and developed further. As in the Kramer et al. (2006) study, the family meeting emerged as an important intervention in this study, as did other specific approaches aimed at enhancing communication, diffusing existing conflict, aligning family perceptions, and mitigating distress. It may be beneficial to utilize these ideas, and the suggestions of the family caregivers in this study, when considering a more deliberate intervention protocol.

Though hospice professionals cited a number of things they did to address conflict in the families they worked with, in many instances family caregivers did not perceive hospice to be actively involved with their family issues. A striking finding is the limited description by caregivers of things hospice staff did to specifically address the conflict they were experiencing. Some caregivers expressed appreciation for staff attempts to help with their personal distress, but in many cases, even this was not perceived as occurring.

The approaches shared by professionals were predominantly reactive in nature, and some admitted to avoiding the conflict all together in many situations. Though "hands off" approaches may sometimes seem most appropriate, professionals have a responsibility to address dynamics that may interfere with comfort and quality of life for patients and families. It is the responsibility of the hospice team, and especially social workers, to educate families on how they can be helpful with family issues, as family

members may not fully understand their role and expertise. All hospice families have distress to some extent, and addressing distress really is routine care provided to all hospice families. Families in conflict may need more assistance and/or a different type of assistance, and hospice professionals may want to strengthen their intervention protocol specific to families in conflict.

The type of assistance provided should depend on assessment of each family's unique needs and receptivity, and intervention can come in many forms. For some families, intervention may be as basic as simply acknowledging how past issues are impacting their current situation. For others, actively working towards resolution and enhanced family functioning may be needed and welcomed. In other cases, intervention might consist of helping the family to set issues aside temporarily to focus on their dying relative. For some families, intervention may mean helping family members cope with the fact that family functioning is not going to change and then working with the family's other skills and strengths. It seems that family conflict more heavily rooted in the family context is less amenable to change than conflict surrounding the end-of-life situation. Because the family context is such a significant element of family functioning, professionals should keep in mind that change may not always be possible.

If family members cannot be rallied together to adequately and/or effectively provide care and support, professionals should seek to minimize caregiver burden and enhance support by broadening the caregiving network outside of the family. In such cases, professionals might help family members to cope with the consequences of

conflict rather than to address the conflict itself. Gaventa (2001) discusses the strategy of creating and energizing caregiving communities, "circles of support" that contain both professional and informal support from friends, family members, neighbors, colleagues, acquaintances, and members of community organizations. This asset based approach, while facilitated by professionals, assumes that communities have the skills and resources to support dying individuals and their families and that professionals are not always the experts. Another such strategy, dubbed "share the care" by its founders, has been presented in a handbook and website designed to help professionals and laypeople to create, organize, and manage a caregiver "family" from friends, relatives, neighbors, business associates, and acquaintances (Capossela & Warnock, 2004). Strategies such as these should be examined further through research.

Intervention related to family conflict should be a team approach; multiple perspectives and sources of expertise are essential. Different family members tend to share information and feelings with different team members and some team members are better at drawing out family issues than others. One discipline may be more appropriate to intervene than another depending on the nature or source of the conflict. For example, if conflict seems to stem from a family history of abuse and conflicted relationships, a social worker may be better equipped to respond, whereas conflict stemming from ideas about medication use may more appropriately be a nurse's domain.

It may be helpful for all hospice professionals to receive training specific to family conflict, as for many, content on family dynamics was not part of their formal

training. Training on prevention, assessment, and intervention of family conflict may give professionals more confidence and competence in their approaches, thereby minimizing the effects of conflict on the family and team. In a number of examples of family conflict provided, hospice professionals suggested that they felt incapable of addressing family conflict or that it was not their responsibility. Enhancing nurse and social worker competence, emphasis on evidence-based practice, and sense of responsibility through educational programming may be a necessity if family needs are to be effectively addressed (Damron-Rodriguez, 2008; Levine, 2008).

Study Limitations

The limitations of this study relate to sample, study design, and measurement, limiting the full interpretation of its results and the conclusions that may be drawn. First, sample characteristics were driven by the traits of the region and those served by the cooperating hospice program. Though the nation's aging population continues to grow more and more diverse, Wisconsin is relatively homogenous with 90% of its people overall and 96.4% of its population age 65 and older identifying as "white" (U.S. Census Bureau, 2000). The cooperating hospice program served mainly small communities surrounded by relatively rural areas in central Wisconsin, an area that is even more homogenous than the state as a whole. Individual and family responses to death and dying, and how families relate with one another at the end-of-life, may vary according to culture and this study did not allow for such comparisons.

An additional sampling issue is that this study involved only families who

accessed hospice care. End-of-life care extends beyond the scope of hospice, ranging from other programs that provide palliative care to services involving active, aggressive, and even invasive measures. Many patients use other programs, not electing hospice due to personal choice, and/or facing barriers to admission. Concerns have surfaced that a number of patient groups lack fair access to hospice, including those without informal caregivers, those who are terminally ill but whose disease trajectory and life expectancy are uncertain, racial and ethnic minorities, people in rural areas, and individuals living in nursing homes (Corless & Nicholas, 2003). Those who are do not access hospice or who opt for other approaches may have different experiences with family functioning and conflict at the end-of-life. Their conflict may manifest differently due to the nature of the care, decisions, and setting in which care takes place.

Second, the cross-sectional nature of this study did not allow for clear understanding of the direction of effects between the family context, conditions, contributing factors, and conflict. The proposed conceptual model suggests that the contributing factors may influence family conflict, though it is equally possible that family conflict influences communication constraints and incongruent perceptions. A related limitation is the limited ability to fully examine the outcomes and consequences of family conflict at the end-of-life. Family caregivers were only interviewed and/or surveyed one time, early in their family member's admission into hospice. As such, they were not able to report on how the conflict evolved over the course of their family members' final days and into the bereavement period. Hospice professionals were able to

report some consequences during the bereavement period, though hospice involvement is often quite limited during that time, with some families opting out of bereavement services.

An additional design limitation is that only one family member was asked to participate in the study, not allowing for the examination of a variety of family perspectives. It is certainly possible that different family members view their situation and their family differently. As suggested by Waldrop (2006), asking multiple family members to participate in research may be burdensome for a family who is actively engaged in caregiving for someone who may die soon. Due to the desire to minimize burden for families and the need to keep the scope of the study manageable, the researcher decided to focus on primary caregiver and hospice staff perceptions.

Third, some of the measures utilized in the quantitative analysis were limited. First, there were a number of measures containing only one or two items, such as "coming out of the woodwork," "family involvement," and "death anxiety." Second, the care needs of the patient were assessed from the primary caregiver's perspective, reflecting their impressions, not professional assessment. Though the primary caregiver's judgments may have been valid, in some instances they may have underestimated or overestimated the patient's care needs. Third, because this is a relatively new area of inquiry, there were not many existing measures available to capture the study variables. For example, the family conflict and prior family conflict measures were just recently developed and have not yet been widely tested. Though there were a number of instances

in which the direction of effects were as anticipated and/or approaching significance, these measurement limitations, along with the relatively small sample size, may have influenced the ability to detect all of the potential relationships among variables.

These limitations may further explain why some themes that arose during qualitative analysis were not supported during quantitative analysis. Variables from the qualitative model may not have been measured as perfectly as possible. Further, because those interviewed had higher levels of conflict, communication constraints, and family asserting control than those not interviewed, and hospice professionals may have been likely to discuss more severe cases of conflict they encountered in their practice, the qualitative results are likely reflecting more intense family conflict experiences.

Directions for future research

In response to the methodological limitations of this study, additional research should examine how family conflict at the end-of-life is experienced by people from diverse groups across society and by those outside of the hospice realm. Some research conducted by Kramer and colleagues (Kramer et al., 2006; Kramer et al., 2009) has touched on these aspects, but further investigation is needed. Time-ordered data are also needed to examine the direction of proposed relationships and to gain perspective from family members at multiple points during the end-of-life experience. Further, future researchers might consider gaining the insights of multiple family members to more fully understand the family's experience and to prevent one-sided accounts from biasing our understanding of this phenomenon.

In terms of content, a next logical step for this line of research is to further examine the professional interventions that hospice professionals in this study reported using to address family conflict. Exploring interventions in a qualitative sense was important to get a beginning understanding of how professionals approach family conflict, but this should be followed up with a more rigorous examination of the extent to which these approaches are effective. Since the family meeting emerged as a key intervention reported by hospice staff, additional research should examine its structure and usefulness to staff and families involved with family conflict. Key to any intervention process is the ability to effectively assess the family context. Further research might aim at developing and testing family conflict specific assessment protocols.

Additionally, further measurement and testing of each the variables proposed in the conceptual model and how they relate to one another is needed. Some such testing took place in this study and in the study by Kramer et al. (2009), but examination encompassing additional variables and avoiding the methodological limitations of each study is warranted. In particular, investigation of the potential outcomes and moderating factors related to family conflict is needed as such examination was beyond the scope of this study. For example, it might be interesting to examine social support as a moderator of contributing factors on conflict.

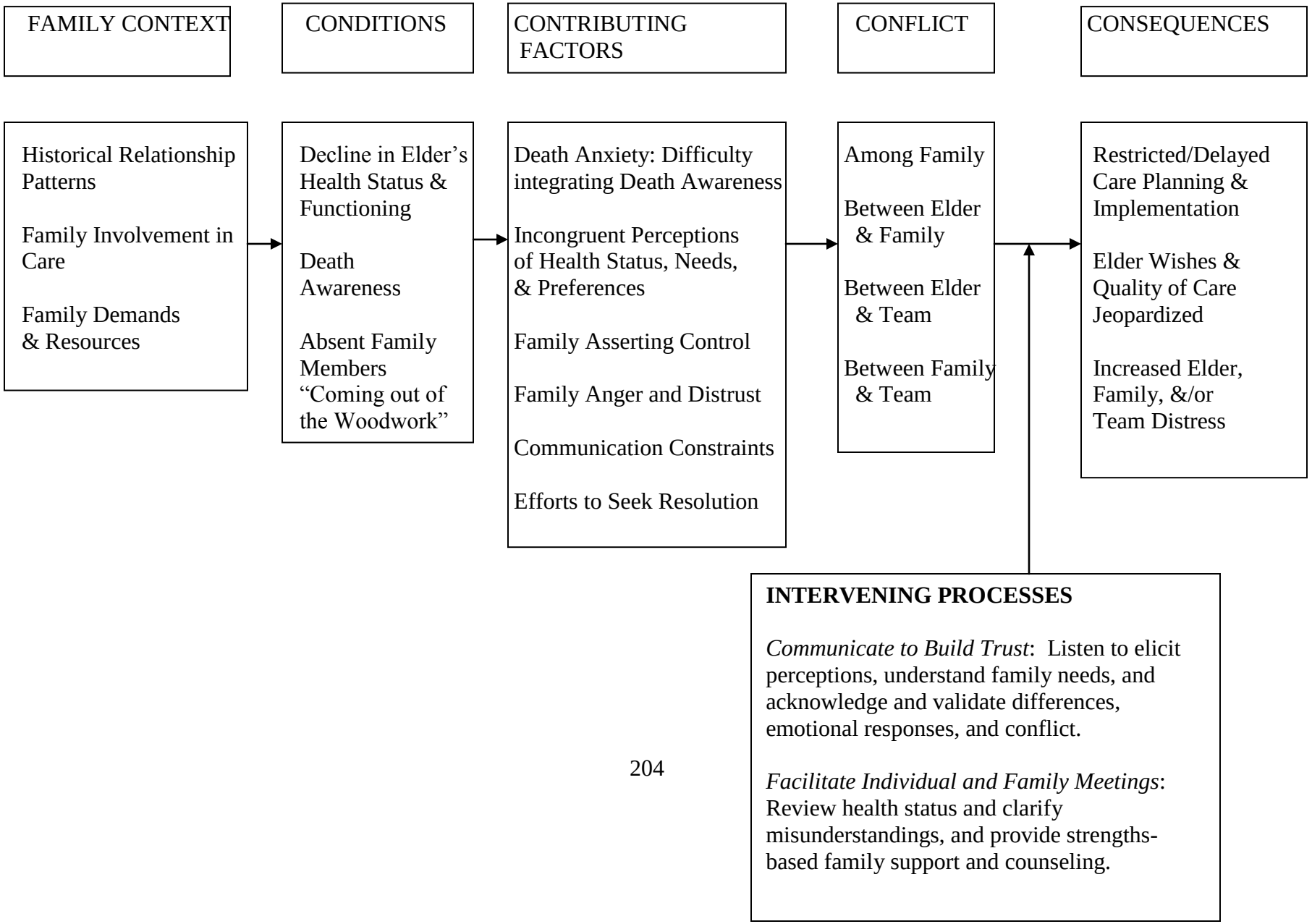
Other content areas worthy of further investigation involve forms of conflict that manifested in this study but were not included in the conceptual model due to the scope and focus of the study. These forms of conflict might be examined further to provide a

more comprehensive picture of family conflict at the end-of-life. Internal conflict, which is conflict that occurs within the caregiver but does not necessarily involve other individuals, appeared to be significant for this population. An understanding of internal conflict as its own issue as well as how it might relate to family conflict at the end-of-life may be important to best serve patients and family members. Conflict taking place during the bereavement period might also be examined further to better understand the family experience over time. Preliminary data collected during this study suggests that post-death conflict may be an extension of previous conflict, or may be new conflict as family members have to make post-death decisions or as they grieve differently. Family conflict at the end-of-life as a potential predictor for complicated grief has been cited in the literature but not fully examined. Because hospice and other programs serve grieving families, an understanding of bereavement-related conflict may be imperative to their work. Examples of conflict among professionals also surfaced during this study. Though this aspect was not included because of its lack of focus on the family, it may have important implications for practice. A look at conflict involving other providers (i.e. between hospice and nursing homes or between the family and private hire caregivers) and conflict among the hospice team may broaden our understanding of the issues that families and professionals in serving patients at the end-of-life.

The qualitative data collected in this study is a starting point for revealing, in rich detail, the unseen suffering of caregivers involved with family conflict. There seems to be much that is hidden by caregivers, either deliberately or not, in their attempt to

minimize conflict and preserve the family system. It may be useful for professionals to more fully comprehend this depth of suffering so that they may be better prepared to offer support and assistance. Our tendency is to think that there should be a nice, easy death for the dying person and that if professionals could just address the conflict that comes up everything would go so much smoother. Yet, professionals may not fully appreciate the complexity of the family systems, the cruelties that have taken place, and the depth of dysfunction that may be very difficult to touch with a simple intervention. Additional research is needed to further reveal these family dynamics and bring them to awareness for all professionals who work with patients and families at the end-of-life. This awareness may give them greater perspective on family functioning and needs, better equipping them to intervene effectively, empathically, and with heightened sensitivity.

Appendix 1. Explanatory Matrix of Family Conflict at the End-of-Life *(Kramer, Boelk, & Auer, 2006)*



Appendix 2. Family Caregiver Recruitment Protocol

Hospice Family Caregiver Study: Social Worker Instructions and Script

Criteria for Participation: The survey will be offered at every admission (home, CBRF, House of Dove, inpatient, nursing home), unless the patient is perceived as "actively dying." There may be situations in which the social worker believes that introducing the survey at the time of admission would cause undue distress to the caregiver. For example if the caregiver is experiencing anxiety attacks or is assessed as severely depressed at the time of admission, the social worker may decide that the timing is not suitable for introducing the survey. In these situations, the social worker will document the specific reason for this clinical judgment, and then offer the survey at the following visit.

Please remember that family caregivers will be the best judge as to whether or not they are capable and willing to complete this brief survey and/or participate in a future interview (if they are eligible). The consent form will fully describe their rights and responsibilities that will allow them to make this decision for themselves. It is important during the duration of the study that all patients and family caregivers who are eligible are provided with the opportunity to participate so that more accurate response rates and representative study findings may be obtained. If the most highly functioning family members are the only one likely to be offered the survey, it will compromise the potential value of the knowledge gained.

Protocol

1. *Admissions Coordinator:* When possible, the admissions coordinator will notify patient and/or caregiver of the study during the referral process. The admissions coordinator will briefly explain that a) the survey is being done because hospice is interested in better understanding the experiences and needs of family members of patients enrolled in hospice in order to improve care, and b) the social worker will tell them more about it during the admission visit.
2. *Social Worker:* At the conclusion of the admission visit, either jointly or individually, the social worker will then introduce and briefly explain the study to the patient and caregiver [see script on p. 2] and provide a copy of the consent form describing the study in detail.
3. The social worker will review the consent form with the patient and obtain verbal and written patient consent.
4. If patient consent is obtained, the social worker will review the consent form with the caregiver and obtain verbal and written caregiver consent.
5. If caregiver consent is obtained, the social worker will leave the survey packet with the caregiver.
6. The social worker will mail the patient and caregiver consent forms to Amy Boelk in a self-addressed envelope.
7. For tracking purposes, the social worker will notify the admissions coordinator of 1) whether the survey was offered, and if not, reason for that decision, 2) whether the patient consented and if not, reason stated, and 3) whether the caregiver consented and if not, reason stated. If aspects of this process are completed at a later social work visit, the social worker will notify the admissions coordinator of that as well.

Appendix 2. Family Caregiver Recruitment Protocol (continued)

Special Circumstances

1. In situations when the patient is unable to physically sign consent but mentally competent to give verbal consent, the social worker will ask for verbal consent, ask if they have permission to sign and date on behalf of the patient, and document as such on the consent form.
2. In situations when the patient is unable to provide consent due to incapacitation (e.g., severe dementia, coma), the designated power of Attorney for health care or guardian will serve as proxy. If no power of attorney or guardian has been appointed the family member most involved in patient's care will serve as proxy.
3. If there is no identified primary caregiver upon admission, social worker will explain the study to the patient, and if the patient gives consent, ask him or her which family member is most involved/appropriate for participation in the study. The social worker will then explain the study and provide the survey packet to the caregiver at the next visit.
4. If the primary caregiver lives at a distance, and/or is not likely to be present for social work visits, the social worker will notify the caregiver via phone of the study and mail the survey packet to them at the social worker's earliest convenience.

Recommended Script for Joint Person Interview

To both patient and caregiver:

Our hospice is interested in better understanding the experiences and needs of family members of patients enrolled in our program so that we may improve our services to families. As such we are working with a social work researcher who has designed a brief survey for family members to complete. [Give consent form to patient and family member]. We are inviting all family members who are most involved with caring for someone to complete a short survey that takes about 15-20 minutes. Of those who complete surveys, 15 will be invited to participate in a longer interview. This form describes the purpose of the study, the kinds of things that are asked about in the survey, the risks, the benefits and how confidentiality will be protected. Participation is completely voluntary and will not affect hospice care received in any way. We hope that this project will help us to provide better care to families in the future. Family members who complete the surveys will receive a $5 gas card and those who are interviewed will receive a $10 gas card.

To patient:

Because your family member will be asked for information regarding such things as your age, gender, health, living situation, needs, and help you receive, we need your permission for them to participate. We don't foresee any risks to you for allowing your family member to participate. Would you be willing to allow your family member to participate in this study? [If yes, thank patient, review the consent form with the patient, obtain signature or verbal consent, and go to "to caregiver" script below. If no, thank patient and caregiver for considering and end discussion of study].

Appendix 2. Family Caregiver Recruitment Protocol (continued)

To caregiver:

With your family member's permission, do you think you might be willing to receive a copy of this short survey to complete at a time that is convenient for you? [If no, thank patient and caregiver for considering and end discussion of study. If yes, thank caregiver, review the consent form with the caregiver, obtain caregiver signature and contact information on consent form, provide envelope with enclosed survey and instructions, and continue]. In this envelope, you will find the survey with instructions and a return envelope. Feel free to complete the survey at any time during this next week that is convenient for you, and then use the attached postage paid envelope to mail it to the researcher. You may receive a call from the researcher thanking you for participating and asking if you have questions about the survey. Thanks so much for taking the time to participate in this study.

Recommended Script for Patient Only Interview

To patient:

Our hospice is interested in better understanding the experiences and needs of family members of patients enrolled in our program so that we may improve our services to families. As such we are working with a social work researcher who has designed a brief survey for family members to complete. [Give consent form to patient]. We are inviting all family members who are most involved with caring for someone to complete a short survey that takes about 15-20 minutes. Of those who complete surveys, 15 will be invited to participate in a longer interview. This form describes the purpose of the study, the kinds of things that are asked about in the survey, the risks, the benefits and how confidentiality will be protected. Participation is completely voluntary and will not affect hospice care received in any way. We hope that this project will help us to provide better care to families in the future. Family members who complete the surveys will receive a $5 gas card and those who are interviewed will receive a $10 gas card. Because your family member will be asked for information regarding such things as your age, gender, health, living situation, needs, and help you receive, we need your permission for them to participate. We don't foresee any risks to you for allowing your family member to participate. Would you be willing to allow your family member to participate in this study? [If yes, review the consent form with the patient, obtain signature or verbal consent, and continue. If no, thank patient for considering and end discussion of study]. Thank you for participating. I will be talking with your family member about the study in the near future.

Recommended Script for Caregiver Only Interview

To caregiver:

Our hospice is interested in better understanding the experiences and needs of family members of patients enrolled in our program so that we may improve our services to families. As such we are working with a social work researcher who has designed a brief survey for family members to complete. [Give consent form to family member]. We are inviting all family members who are

Appendix 2. Family Caregiver Recruitment Protocol (continued)

most involved with caring for someone to complete a short survey that takes about 15-20 minutes. Of those who complete surveys, 15 will be invited to participate in a longer interview. This form describes the purpose of the study, the kinds of things that are asked about in the survey, the risks, the benefits and how confidentiality will be protected. Participation is completely voluntary and will not affect hospice care received in any way. We hope that this project will help us to provide better care to families in the future. Family members who complete the surveys will receive a $5 gas card and those who are interviewed will receive a $10 gas card. Your family member has agreed to allow you to participate in the study. Do you think you might be willing to receive a copy of this short survey to complete at a time that is convenient for you? [If no, thank caregiver for considering and end discussion of study. If yes, thank caregiver, review the consent form with the caregiver, obtain caregiver signature and contact information on consent form, provide envelope with enclosed survey and instructions, and continue]. In this envelope, you will find the survey with instructions and a return envelope. Feel free to complete the survey at any time during this next week that is convenient for you, and then use the attached postage paid envelope to mail it to the researcher. You may receive a call from the researcher thanking you for participating and asking if you have questions about the survey. Thanks so much for taking the time to participate in this study.

Appendix 3. Family Caregiver Introductory Letter

Dear Family Member,

As you have learned from the hospice social worker, I am interested in learning more about the experiences and needs of family members of patients enrolled in hospice. Family members who are most involved with caring for persons admitted to the program are being invited to complete a short 15-20 minute survey. Fifteen family members who complete the survey will additionally be invited to participate in two interviews.

Participation is completely voluntary and will not affect the care that your family member receives in any way. The information you provide will be kept confidential. Family members who complete the survey will receive a $5 gas card and those who are interviewed will additionally receive a $10 gas card for each interview.

I thank you in advance for agreeing to participate in this study. Please complete the enclosed ***Family Caregiver Survey*** and **return the survey in the return envelope provided**. I will then mail you the complimentary gas card to thank you for your participation. You may receive a phone call from me to thank you for participating and to ask if you have questions about the survey. Also, please feel free to contact me if you have any questions or concerns about this project. I can be most easily reached at (715) 346-3603. Again, thank you for your time.

I appreciate the opportunity to learn from you. It is my hope, and the hope of Ministry Home Care that information gathered through this study will help improve care for future hospice families. Your input is very important. I hope to hear from many family members so that I can get a good sense for the issues people face when enrolled in hospice.

Sincerely,

Amy Boelk, MSSW
Assistant Professor & Field Coordinator
University of Wisconsin-Stevens Point, Sociology Department
Doctoral Student
University of Texas, Austin, School of Social Work

Enclosures

Appendix 4. Survey Follow-up Script

My name is Amy Boelk, and I am a researcher involved with hospice. Is your family member still enrolled in hospice? If no, offer condolences and end call. If yes, continue.

The hospice social worker talked with you about my study and left a survey for you to complete. Thank you for agreeing to participate in this research project. I know that this may be a very difficult time for you, but we know so very little about the experiences of family members who are caring for someone who is in hospice. Your input would be really valuable to me and to future hospice families.

Have you had a chance to complete the survey yet?

- If yes:
  - Thank you for taking the time to do this. I look forward to receiving it, and I wish you and your family the best.
- If no:
  - Do you need another copy?
  - Do you have any questions about the survey?
  - Would you like me to stop by to help you with the survey?
  - When do you think you might have a chance to complete it?
  - Thank you so much for your time, and I wish you and your family the best.

Appendix 5. Family Caregiver Survey

Hospice Primary Caregiver Survey

This survey is designed to help us better understand the needs and experiences of persons receiving hospice care and their family members. Your responses will be kept strictly confidential. In order to ensure your privacy, please do not place any identifying marks on this form. Your participation is entirely voluntary. If there are any questions you do not wish to answer, you may leave them blank. The survey should take about 15-25 minutes to complete. Please read each question carefully and fill in or check (✓) the response that BEST answers each question.

SECTION 1. These first questions ask about your family member who is enrolled in hospice and about the type and amount of assistance that you provide to him or her.

1. How old **(in years)** is your family member?
   _____

2. Is your family member male or female?
   _____ Male
   _____ Female

3. What is his/her **primary illness** (the one that caused him/her to enroll in hospice)?
   _____ Cancer
   _____ Heart disease
   _____ Lung disease
   _____ Kidney disease
   _____ Alzheimer's disease/dementia
   _____ ALS
   _____ Failure to thrive
   _____ Other, please specify _____

4. How long has he/she had this illness (please indicate number of **months and/or years**)?
   _____

5. How quickly has this illness progressed?
   _____ Not at all quickly
   _____ Somewhat quickly
   _____ Moderately quickly
   _____ Very quickly
   _____ Extremely quickly
   _____ Don't know/ can't say

6. Does he/she have any other serious physical or mental illnesses/conditions?
   _____ No
   _____ Yes → 6a. If yes, please name each illness and indicate how long he/she has had it (in **months and/or years**)

Illness	**Number of months and/or years**

7. How are you related to the family member you are helping?
   _____ He/she is my spouse
   _____ He/she is my parent
   _____ He/she is my child
   _____ He/she is my sibling
   _____ He/she is my significant other, but we're not married
   _____ Other, please specify_____

8. Please look at the following list of activities. In the first column, please place a check (✓) by the ones that your family member needs help with. In the second column, please place a check (✓) by the ones that you help your family member with.

Activity	**Needs help**	**I provide help**
Bathing		
Dressing		
Toileting		
Transferring		
Incontinence		
Feeding		
Shopping		
Food Preparation		
Transportation		
Laundry		
House Cleaning		
Medications		
Finances		
Emotional Support		
Decision Making		

9. Other than you, how many other family members provide help with the activities listed above (in question 8)?

   _____

10. How **physically difficult** is it for you to help your family member?
    _____ Very difficult
    _____ Somewhat difficult
    _____ A little difficult
    _____ Not at all difficult

11. How **emotionally difficult** is it for you to help your family member?
    _____ Very difficult
    _____ Somewhat difficult
    _____ A little difficult
    _____ Not at all difficult

12. How long have you been helping this family member (indicate number of **years and/or months**)?

_____

13. To what extent do you wish other family members were helping more?
    _____ Not at all
    _____ A little bit
    _____ Somewhat
    _____ Quite a bit
    _____ Very much

14. Some families say that when a family member becomes seriously ill, other family members suddenly "come out of the woodwork." This means that family members who were not previously in regular contact suddenly become more involved. How much has this occurred as a result of your family member's illness?
    _____ Not at all
    _____ A little bit
    _____ Somewhat
    _____ Quite a bit
    _____ Very much

15. Besides hospice, what other community programs is your family member involved in (please check all that apply)?
    _____ None, just hospice
    _____ Meals on wheels/ home delivered meals
    _____ Lifeline
    _____ Family Care
    _____ Community Options Program (COP)
    _____ Other, please specify_____

16. Where is your family member living right now? (note: if your family member is currently hospitalized, please indicate where he/she typically lives)
    _____ In their own home
    _____ In a family member's home
    _____ In assisted living or a group home
    _____ House of the Dove
    _____ In a nursing home
    _____ Other, please specify_____

17. Do you live with your family member?
_____ No
_____ Yes

18. Are you currently providing care for any other family members or friends because of an illness, disability, or advanced age?
_____ No
_____ Yes, please specify their relationship to you_____

19. How many children under the age of 18 are living in your home?
_____

<u>SECTION 2.</u> This next set of questions is about how your family members interact with and get along with one another. The term "family" refers to those persons <u>you</u> consider to be your family, including the family member you are currently helping.

Please indicate how much you agree or disagree with each of the following statements.		**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
20.	Planning activities is difficult because we misunderstand each other.	☐	☐	☐	☐	☐
21.	In times of crisis we can turn to each other for support.	☐	☐	☐	☐	☐
22.	We cannot talk to each other about the sadness we feel.	☐	☐	☐	☐	☐
23.	Individuals are accepted for what they are.	☐	☐	☐	☐	☐
24.	We avoid discussing our fears and concerns.	☐	☐	☐	☐	☐
25.	We can express feelings to each other.	☐	☐	☐	☐	☐
26.	There are lots of bad feelings in the family.	☐	☐	☐	☐	☐
27.	We are able to make decisions about how to solve problems.	☐	☐	☐	☐	☐

28.	We don't get along well together.	☐	☐	☐	☐	☐
29.	We confide in each other.	☐	☐	☐	☐	☐

SECTION 3. The next three questions are about past family disagreements and difficulties.

Prior to your family member's illness, how much did family members…		**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
30.	Have trouble talking openly with one another?	☐	☐	☐	☐	☐
31.	Have serious arguments with one another?	☐	☐	☐	☐	☐
32.	Insult or yell at one another?	☐	☐	☐	☐	☐

SECTION 4. Many family members have said that caring for a loved one who is seriously ill can be stressful and cause disagreements or difficulties in the family that may or may not have been the way they related to one another in the past. This set of questions asks about conflict your family may be experiencing.

As you think about your family since your relative was diagnosed with a life-threatening illness, how much do any family members…		**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
33.	Disagree or argue with one another about health care decisions for your relative?	☐	☐	☐	☐	☐
34.	Get along with one another when making decisions?	☐	☐	☐	☐	☐
35.	Disagree or argue with one another about your relative's illness or physical condition?	☐	☐	☐	☐	☐
36.	Make decisions about care provided that other family members did not want?	☐	☐	☐	☐	☐

37.	Disagree or argue with a family member about the way they were treating your relative (e.g., not visiting)?	☐	☐	☐	☐	☐
38.	Avoid one another because of the disagreements?	☐	☐	☐	☐	☐
39.	Disagree or argue about certain family members not pulling their weight to help provide care for your relative?	☐	☐	☐	☐	☐
40.	Work together to provide care for your relative?	☐	☐	☐	☐	☐
41.	Disagree or argue about beliefs or religious differences?	☐	☐	☐	☐	☐
42.	Insult or yell at one another?	☐	☐	☐	☐	☐
43.	Disagree or argue about what is meant by "a good death"?	☐	☐	☐	☐	☐
44.	Disagree or argue about how money is being spent or being used?	☐	☐	☐	☐	☐
45.	Disagree or argue about where your relative should live out his/her remaining days?	☐	☐	☐	☐	☐
46.	Get help from health care professionals to resolve family disagreements or problems?	☐	☐	☐	☐	☐
47.	Continue to feel hurt or resentment from any disagreements or problems?	☐	☐	☐	☐	☐
48.	From your perspective, how upsetting are these conflicts to you when they occur?	☐	☐	☐	☐	☐

<u>SECTION 5.</u> The next set of questions is about the support that you, as a caregiver, have in your life.

Please tell me how much you agree or disagree with each of the following statements.		**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
49.	There is a special person who is around when I am in need.	☐	☐	☐	☐	☐

50.	There is a special person with whom I can share my joys and sorrows.	☐	☐	☐	☐	☐
51.	My family really tries to help me.	☐	☐	☐	☐	☐
52.	I get the emotional help and support I need from my family.	☐	☐	☐	☐	☐
53.	I have a special person who is a real source of comfort to me.	☐	☐	☐	☐	☐
54.	My friends really try to help me.	☐	☐	☐	☐	☐
55.	I can count on my friends when things go wrong.	☐	☐	☐	☐	☐
56.	I can talk about my problems with my family.	☐	☐	☐	☐	☐
57.	I have friends with whom I can share my joys and sorrows.	☐	☐	☐	☐	☐
58.	There is a special person in my life who cares about my feelings.	☐	☐	☐	☐	☐
59.	My family is willing to help me make decisions.	☐	☐	☐	☐	☐
60.	I can talk about my problems with my friends.	☐	☐	☐	☐	☐
61.	I get support from my faith network (church, synagogue, prayer group, other).	☐	☐	☐	☐	☐

SECTION 6. The next few questions are about your feelings about death.

Please indicate how much you agree or disagree with each of the following statements.		**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
62.	The uncertainty of not knowing what happens after death worries me.	☐	☐	☐	☐	☐

63.	I have an intense fear of death.	☐	☐	☐	☐	☐
64.	The fact that death will mean the end of everything as I know it frightens me.	☐	☐	☐	☐	☐
65.	I am disturbed by the finality of death.	☐	☐	☐	☐	☐
66.	The prospect of my own death arouses anxiety in me.	☐	☐	☐	☐	☐
67.	The subject of life after death troubles me greatly.	☐	☐	☐	☐	☐
68.	Death is no doubt a grim experience.	☐	☐	☐	☐	☐
69.	Thinking about my family member's death is very difficult for me.	☐	☐	☐	☐	☐

SECTION 7. This next set of questions asks about how much your family has discussed and planned for your family member's future care.

Please indicate how much you agree or disagree with each of the following statements.		**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
70.	My family discussed our family member's wishes for care **before** he/she became ill.	☐	☐	☐	☐	☐
71.	My family discussed our family member's wishes for care **after** he/she became ill.	☐	☐	☐	☐	☐
72.	My family planned for our family member's future care needs **before** he/she became ill.	☐	☐	☐	☐	☐
73.	My family planned for our family member's future care needs **after** he/she became ill.	☐	☐	☐	☐	☐
74.	I feel like I understand my family member's wishes.	☐	☐	☐	☐	☐

75.	The rest of the family understands my family member's wishes.	☐	☐	☐	☐	☐
76.	Family members share similar views about how the health care wishes of our family member should be carried out.	☐	☐	☐	☐	☐
77.	Family members share similar views about the health care needs of our family member.	☐	☐	☐	☐	☐
78.	Family members share similar views about where our family member should be cared for.	☐	☐	☐	☐	☐

79. My family member completed a Power of Attorney for Health Care
_____ Before he/she became ill
_____ After he/she became ill
_____ Not at all
___ __ Don't know/can't say

80. My family member completed a Living Will
_____ Before he/she became ill
_____ After he/she became ill
_____ Not at all
_____ Don't know/can't say

SECTION 8. This next set of questions addresses how you have been feeling. Below is a list of the ways you might have felt or behaved.

Please indicate how often you have felt or behaved this way during the past week.		**Rarely/ None (less than 1 day)**	**Some/ A little (1 to 2 days)**	**Occasionally (3 to 4 days)**	**Most/ All of the time (5 to 7 days)**
81.	I did not feel like eating; my appetite was poor.	☐	☐	☐	☐
82.	I felt depressed.	☐	☐	☐	☐
83.	I felt that everything I did was an effort.	☐	☐	☐	☐

84.	My sleep was restless.	☐	☐	☐	☐
85.	I was happy.	☐	☐	☐	☐
86.	I felt lonely.	☐	☐	☐	☐
87.	I felt that people were unfriendly.	☐	☐	☐	☐
88.	I enjoyed life.	☐	☐	☐	☐
89.	I felt sad.	☐	☐	☐	☐
90.	I felt that people disliked me.	☐	☐	☐	☐
91.	I could not get "going."	☐	☐	☐	☐

SECTION 9. This final set of questions asks about your own background.

92. How old (**in years**) are you?

_____

93. Are you male or female?

_____ Male
_____ Female

94. Which of the following best describes your employment status?

_____ Retired
_____ Employed part time
_____ Employed full time
_____ Not employed
_____ Other, please describe _____

95. To what extent have your caregiving responsibilities interfered with your ability to meet your work responsibilities?
_____ Not at all
_____ A little
_____ Somewhat
_____ Quite a bit
_____ Very much
_____ Not applicable (I do not work)

96. How would you rate your own physical health?
_____ Poor
_____ Fair
_____ Good
_____ Excellent

97. What is your race/ethnicity?
_____ White, Non-Hispanic
_____ Hispanic/Latino
_____ African American
_____ Asian American
_____ Native American/American Indian
_____ Other, please describe _____

98. What is the highest level of education you have completed?
_____ Less than high school
_____ High school degree
_____ Some college (no degree earned)
_____ Two-year college/associate's degree
_____ Four-year college degree
_____ More than four-year college degree

99. What is your yearly household income?
_____ Less than $10, 000
_____ $10,001- 20,000
_____ $20,001- 35,000
_____ $35,001- 50,000
_____ $50,001- 75,000
_____ $75,001- 100,000
_____ $100,001 or more

Thank you for your participation in this research. If you have any questions or comments about this research, please write in the space below.

Appendix 6. Family Caregiver Interview Schedule

As you know, you were invited to participate in this interview because you noted in the survey that there have been some disagreements or arguments among your family members since your relative became ill. I'd like to learn from you what those disagreements have been about, how they developed, and what is happening as a result.

1. Could you describe what has been going on? (What have disagreements been about? Who is involved? How are they involved? How long has this been going on?)
2. Could you share specific examples of conflict?
3. What seems to be causing disagreements in your family?
4. Many families need to make difficult decisions when caring for a seriously ill relative. Has this been the case for you? What types of decisions have you had to make as a family? Has this resulted in conflict?
5. How does your family communicate? (How does the way your family communicates effect the disagreements or conflicts that have arisen?)
6. How do you view your family member's condition? (How serious do you think it is? What do you think is going to happen?)
7. Do you think other family members agree with you?
8. What is happening as a result of family disagreements? (Who does it affect and how? How does it affect you, the patient, and other family?)
9. Have family members tried different ways to resolve the conflict? (If so, how did it go?)
10. How has the hospice staff been involved in or responded to these conflicts?

Appendix 6 (continued). Family Caregiver Interview Schedule

11. Overall, how helpful has the hospice staff been in helping your family with these disagreements?

    Not at all A little bit Somewhat Quite a bit Very much

12. What have they done that has been most helpful?

13. Is hospice making the conflict worse in any way?

    Yes No

14. If yes, how?

15. Do you think your family could use additional help with these difficulties?

    Yes No Not sure

16. If yes, what kind of help might be useful?

17. Do you think anything can be done to make this situation better?

    Yes No Not sure

18. If yes, what would help?

19. What can hospice do to help?

Thank you for meeting with me. You have certainly given me some useful information. I appreciate the opportunity to hear your perspective on this. I wish you and your family the best in caring for your family member.

Appendix 7. Focus Group Guide

As you know, I am Amy Boelk, and I am doing my dissertation research here on the topic of family conflict at the end-of-life. In addition to talking with caregivers, I want to get your take on this topic. I perceive you as the experts because what I'm trying to understand is something that it sounds like you deal with a lot. I want to say first of all that since we have the tape recorder on, it's helpful if we speak one at a time and try to speak clearly. I'm sure that won't be a problem, but if people are jumping in on top of one another it will be harder to transcribe the interview. I will transcribe it word for word. Your names won't be associated with your comments on the tapes at all. What I'll do is look at themes and what people are talking about generally after I transcribe the meetings. It's really helpful when you're sharing your thoughts about something if you have a particular example that can help illustrate what you're saying because it's really easy when we're talking about these issues to talk in generalities. I guess I want you to kind of imagine that I'm from Mars. I know nothing about this topic and so the more detail you can give to provide with examples of what you're saying, it would be really helpful. And, I think make the data richer. The other thing is that I welcome contradictory opinions about things; we don't have to come out of here with all of you agreeing about how you think about family conflict or having the same kinds of experiences. There are no right or wrong answers to my questions. I just want you to feel free to share your perspectives. Everyone's input is really important. Also, I want you to know that I am not evaluating you. Though we may talk about the work you do and strategies you have tried, I am not here to judge your effectiveness or capabilities. I am simply trying to learn about what goes on related to family conflict. I would like to start with brief introductions. I know that you all know each other, but it would be helpful to me if you could just share your name, position here, and how long you have worked in hospice.

1. There are a lot of ways to define conflict, but I would like to know how you define it. What is family conflict? (How would you define it?)
2. Are there different types of conflict? (If so, what are they?)
3. Can you think of specific examples that you could describe that clearly illustrate situations in which family conflict was present?
4. How common is family conflict here at hospice? (e.g., what percentage of families on your current caseload have conflict?)

Appendix 7 (continued). Focus Group Guide

5. What do you think causes conflict? (What contributes to it? Can you share specific examples of these causes and contributing factors?)
6. What happens as a result of family conflict? (How does it influence the care you provide? How does it impact you? The patient? The family? Could you share some examples of this?)
7. What strategies do you use to address family conflict?
8. To what extent are you successful in addressing conflict? (Are there types of conflict that you feel you can address more successfully?)
9. Is there anything you do to prevent conflict from developing?
10. What challenges do you face in working with families who are in conflict?
11. Is conflict all bad? (Are there positive outcomes of conflict that you have witnessed? What contributed to more positive outcomes?)

Thank you so much for meeting with me. Your ideas have really helped me to understand the issue of family conflict more fully. I look forward to reviewing these discussions further and sharing the collective results with you after I am done analyzing them.

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